# STATE TITLE V BLOCK GRANT NARRATIVE STATE: PR

APPLICATION YEAR: 2006

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#### I. GENERAL REQUIREMENTS

#### A. LETTER OF TRANSMITTAL

The Letter of Transmittal is to be provided as an attachment to this section.

### **B. FACE SHEET**

A hard copy of the Face Sheet (from Form SF424) is to be sent directly to the Maternal and Child Health Bureau.

#### C. ASSURANCES AND CERTIFICATIONS

By signing the SF424 Form and submitting the Title V Block Grant (BG) Application for 2005-2006, the Puerto Rico Department of Health (PRDoH) is committed to comply with all requirements established by OBRA'89 (PL 104-193, 1996). Funds allotted to PR will only be used for addressing the identified needs of women in their reproductive age, their infants, children and adolescents, including those with special needs and their families; and for the proper management and implementation of the action plan as described in the application. The allotted funds will be fairly distributed across all geographical areas for the different MCH population groups in accordance to the mandate (30-30-10).

Under any circumstance the Title V Block Grant funds will be used for construction or the purchase of land.

We will comply with all applicable requirements of other federal laws, executive orders, regulations and policies governing this program.

The undersigned agrees that the PRDoH will comply with the Public Health Service terms and conditions if the grant is awarded as a result of the submitted application.

Additionally, we certify that services will be rendered in a smoke-free environment, to provide a drug-free workplace in accordance with 45 CFR Part 76, and to comply with the prohibition of using federal funds to support any activity regarding lobbying or its appearance to.

#### D. TABLE OF CONTENTS

This report follows the outline of the Table of Contents provided in the "GUIDANCE AND FORMS FOR THE TITLE V APPLICATION/ANNUAL REPORT," OMB NO: 0915-0172; published June, 2003; expires May 31, 2006.

## E. PUBLIC INPUT

Public input was obtained from a wide array of stakeholders including, but not limited to, women in their reproductive age, adolescents, front line providers (home visiting nurses and community health workers), regional MCH staff, OB and other perinatal providers, pediatricians collaborators from other agencies and programs serving the MCH population, professional organizations, members of the Healthy Start Consortium (also the Advisory MCH Body), Regional SSDI Interagency Working Groups, etc. In addition, on June 11-12, 2005, through an advertisement in two newspapers of wide circulation, "El Nuevo Dia" and "El Vocero", input was requested from the concerned general public. The draft of the application and Needs Assessment was available for review and input on June 13-14, 2005 in Aguadilla, Bayamón, Caguas, Ponce and San Juan. The draft was reviewed by representatives of two entities. However, no written comments were received. (Please see Methodology of the Need Assessment, Section II for more detail)

# **II. NEEDS ASSESSMENT**

In application year 2006, the Needs Assessment must be provided as an attachment to this section.

## **III. STATE OVERVIEW**

#### A. OVERVIEW

Geography and Political Context

Geography: Puerto Rico (PR) is a Commonwealth of the United States (U.S.). It is the smallest of the Greater Antilles islands located in the Caribbean, about 1,000 miles southeast of Miami and 80 miles West of the U.S. Virgin Islands. The island of PR is 100 miles long and 35 miles wide for an approximate area of 3,500 square miles. Puerto Rico has four main offshore islands--Vieques and Culebra to the east, and Mona and Desecheo to the West. Mona and Desecheo are deserted islands. The population of Vieques and Culebra has to travel to PR in small planes and boats in order to access secondary, and tertiary health care as well as other human services.

The Dominican Republic, another of the Greater Antilles islands, is located west of Puerto Rico. Our proximity allows for mutual tourism and the sharing of economic and cultural resources. However, it also allows the entry of a significant number of illegal immigrants affecting our health care systems as well as our health indicators.

Geographically, the Island is divided in 78 jurisdictions known as municipalities, each headed by a mayor who is elected every four years. The largest municipalities in Puerto Rico are San Juan, the capital; Bayamon, Carolina, Caguas, Arecibo, Mayaguez and Ponce.

The climate of the Island is a tropical maritime one, with an average high temperature of 86oF and a low average temperature of 66.9oF. The Atlantic Ocean borders the North of PR and the Caribbean Sea border the South Coast. Due to its location in the Caribbean, PR is highly vulnerable to the strike of hurricanes.

Political Context: Puerto Rico has been part of the United States since the end of the Spanish-American War (1898), and became a commonwealth in 1952. Politically, the Island resembles the 50 states. Every four years, the people of Puerto Rico elect a governor, 28 senators, and 51 House members to serve in the local government. Puerto Rico's voters also elect a nonvoting delegate to the U.S. House of Representatives.

The United States maintains control over Puerto Rico's military defense, transportation, immigration, foreign trade, and many other areas of governance. Puerto Rican residents contribute to Social Security, serve in the U.S. military, and can be called for military service. They do not pay federal income taxes and do not vote in U.S. presidential elections. Puerto Ricans are eligible to participate in federal government programs, but levels of assistance are typically lower than those provided for people living in the 50 states and the District of Columbia. For example, in 2004-2005, the average monthly payment to families through the Temporary Assistance for Needy Families (TANF) program was \$60 in Puerto Rico, compared with \$454 in New York--the state where Puerto Ricans are most highly concentrated.

In addition to TANF, there are several other federal programs that provide support for low-income children and families in Puerto Rico, including nutritional assistance programs, Head Start, Job Corps, and school lunch programs. Residents of Puerto Rico are not eligible to receive Supplemental Security Income and, because they do not pay federal income taxes, they cannot receive the Earned Income Tax Credit, an important source of support for many low-income working families in the United States.

Economic Profile: Fifty years ago, Puerto Rico was a largely rural island where most people made a living as farmers. Since becoming a commonwealth, Puerto Rico has developed closer economic ties with the United States, with increasing revenue from industry, agriculture, and tourism. While U.S. median household income increased by 7 percent between 1989 and 1999 (adjusting for inflation), median household income in Puerto Rico increased by 24 percent.

However, income levels in Puerto Rico still lag far behind those in the rest of the United States. In

1999, median household income in Puerto Rico was \$14,412. West Virginia's median household income--at \$29,696--was the lowest among the 50 states but was still twice as high as the median income in Puerto Rico. The median household income in New Jersey--at \$55,146--was the highest of the 50 states and was almost four times higher than the median income in Puerto Rico. Among Hispanic/Latino households in New Jersey, median household income was \$39,609, still more than two and a half times the median income in Puerto Rico. The level of poverty declined from 58.9% in 1990 to 48.2% in 2000. On the other hand, the number of families under the poverty threshold level off from 55.3% to 44.6 percent. The economic downturn since 2000 is likely to put an additional strain on the Island's limited resources.

Population: Puerto Rico is one of the most densely populated areas of the world. According to the Census Bureau there were 3,808,610 people living in PR in 2000. This represents a population density of over 1,100 people per square mile, similar to the population density of New Jersey which is the most densely populated state. Over 94.4% of the population resides in the urban areas, where an overwhelming concentration of people are found reaching figures close to 10,000 per square mile.

#### **General Trends**

The population living in Puerto Rico has increased during each decade since the first U.S. census was conducted in 1899. In 1899, there were nearly 1 million people living in Puerto Rico. By 1950 the population had more than doubled, reaching 2.2 million. During the past 30 years, increased migration from Puerto Rico to the U.S. mainland, combined with a decrease in fertility levels, has slowed population growth in the Commonwealth. Between 1970 and 1980, there was an 18 percent increase in the Commonwealth's population, followed by a 10 percent increase during the 1980s and only an 8 percent increase during the 1990s, bringing the total population to 3.8 million. In the United States as a whole, there was a 13 percent increase in the population during the 1990s. (Figure III-1)

The population under age 18 increased from less than 500,000 at the turn of the 20th century to 1.1 million in 1950. The child population increased slightly each decade during the 1950s, '60s, and '70s, but has decreased since then, from 1.2 million in 1980 to 1.1 million in 2000. Therefore, the number of children living in Puerto Rico today is roughly equal to the number of children living there in 1950. Between 1990 and 2000, the number of children in Puerto Rico decreased by 5 percent, compared with a 14 percent increase in the United States. Despite the recent drop in the population under age 18, the number of children in Puerto Rico has more than doubled during the past century.

The proportion of children in the population has also declined in recent decades. Between 1899 and 1960, the share of children in the population hovered around 50 percent. But since then, there has been a steady decline in the percentage of children, from 43 percent of the population in 1970 to 29 percent in 2000. This is only slightly higher than the percentage of children in the United States (26 percent) and is lower than the share of children in the nearby U.S. Virgin Islands (32 percent). The long-term decline in the proportion of children in Puerto Rico's population does not reflect a significant decrease in the number of children but rather an increase in the number of adults relative to the child population. (Figure III-2)

The decline in the proportion of the population under age 18 has been driven by two main factors. First, there has been a long-term decline in fertility rates in Puerto Rico. In 1950, the fertility rate in Puerto Rico was 5.2 births per woman. By 1970, it had fallen to 3.2 births per woman, and by 2000 it had dropped to 1.9 births per woman. The 2000 fertility rate in Puerto Rico was slightly lower than the rate in the United States as a whole (2.1 births per woman) and was substantially lower than the rate for U.S. women of Puerto Rico descent (2.6 births per woman). The decline in fertility rates in Puerto Rico during the 1950s and 1960s has been linked to increasing levels of female sterilization during those decades. Other factors, including a rising age at marriage and an increase in the use of oral contraceptives, have contributed to the decline in recent years, but sterilization continues to play a key role. In fact, the estimated percentage of married women in Puerto Rico who have been sterilized --46 percent--is higher than that of any other country for which we have data.

Second, many young Puerto Ricans and their families have moved to the U.S. mainland in search of

greater job opportunities and higher wages. Between 1995 and 2000, the net movement of people age 5 and over from Puerto Rico to the U.S. mainland exceeded 100,000 migrants. This relatively high level of out-migration could contribute to the decline in the number of children in Puerto Rico in two ways--through the migration of children who come to the U.S. mainland with their parents and through the out-migration of people of reproductive age, which reduces the number of potential births that occur on the Island.

#### Female-Headed Families

Family structure has important implications for children. Children growing up in single-parent families typically do not have access to the economic or human resources available to children growing up in two-parent families. In the United States, the number of single-parent families has risen dramatically over the past three decades, causing considerable concern among policymakers and the public. While local social and cultural norms may influence the situation for children living in single-parent families (for example, they may benefit from extended family support), children in Puerto Rico growing up in single-parent families are still at an economic disadvantage relative to children growing up in families with both parents present in the household. About 44 percent of married-couple families with children were living in poverty in 1999, while among female-headed families with children, 71 percent were living in poverty. In the United States, about 7 percent of married-couple families with children-and 34 percent of female-headed families with children-were living in poverty in 1999.

In 2000, about 27 percent of families with children in Puerto Rico were headed by a female householder. This represents an increase over the share of female-headed families with children in 1990 (22 percent) and is higher than the U.S. average. In the United States, the share of female-headed families increased from 20 percent in 1990 to 22 percent in 2000.

The proportion of female-headed families increased in 48 of the 50 states during the 1990s (Colorado and Utah were the exceptions). In the U.S. Virgin Islands, about 46 percent of families with children were headed by a female householder in 2000, up from 37 percent in 1990. These data suggest that the increase in female-headed households in Puerto Rico followed a trend seen throughout the United States.

#### Poverty

In 1999, more than half of the children in Puerto Rico--58 percent--lived in families with incomes below the poverty line. Puerto Rico's child poverty rate was over three times higher than the child poverty rate in the United States (16 percent). American Samoa--at 67 percent--was the only U.S. state, territory or commonwealth with a higher child poverty rate than Puerto Rico in 1999.

Although poverty levels in Puerto Rico are still quite high, they declined significantly during the 1990s-a period of unprecedented economic growth in the United States. Between 1989 and 1999, the number of children in Puerto Rico living in families with incomes below the poverty line decreased by 18 percent, from 761,789 to 626,521. The percentage of children living in poor families also decreased, from 67 percent in 1989 to 58 percent in 1999. In the United States, the child poverty rate dropped from 18 percent to 16 percent during the 1990s.

The number of families living below the poverty line also declined, from 492,025 in 1989 to 450,254 in 1999. However, the number of female-headed families living in poverty increased by 12 percent, from 142,737 in 1989 to 159,205 in 1999. In 1999, the median income for female-headed families with children in Puerto Rico was \$6,888, compared with \$20,284 in the United States.

Education: According to the Census Bureau the illiteracy rate in 1990 was close to 10% (data is not available for 2000). This proportion of analphabetisms is unacceptable in PR, if we consider the high number of public and private schools available in the Island. In 2004-2005, there were 1,528 public and 672 private schools. The number of students enrolled in the public education system was 575,387 and 133,637 in the private system. It is important to highlight that the number of students has been consistently declining during the last decade. In 2000-2001, the number of students in the public system was 612,024 vs. 575,387 in 2004-2005 (<6%).

In addition to the primary and secondary education system is the higher education system. Over 55 institutions of higher education have been established in PR since 1980. These include four Schools of Medicine; the University of PR School of Medicine which includes the School of Public Health and three private School of Medicine located in Bayamon, Caguas and Ponce. These schools provide a wide array of degrees of health professionals in addition to MD's, Dentists and nurses.

## **High School Dropouts**

During the past 50 years, Puerto Rico experienced a relatively rapid shift from small-scale agricultural production to an industrial and service-oriented economy. This transformation has led to a growing demand for educated workers with high school, college, and postgraduate degrees. In Puerto Rico, as in the United States, a high school diploma is a critical prerequisite for many entry-level jobs as well as for higher education. However, many young adults in Puerto Rico do not graduate from high school. In 2000, about 14 percent of 16-to-19-year-olds in Puerto Rico were high school dropouts (not enrolled in school and non high school graduates). The high school dropout rate in Puerto Rico was relatively high compared with most states--exceeded only by Arizona (15 percent) and Nevada (16 percent). In the United States as a whole, about 10 percent of 16-to-19-year-olds were high school dropouts in 2000. Currently, it is estimated that nearly 40% of children who begin the first grade will desert from school before they reach the 12th grade.

However, even though the dropout rate in Puerto Rico remains relatively high, there has been considerable improvement in this measure since 1990, when 22 percent of 16-to-19-year-olds were not enrolled in school and not high school graduates. It is important to highlight that in the case of females, pregnancy is the most common cause for school dropout.

#### The Need for Child Care

In this report, the need for child care is measured as the percentage of children under age 6 living in families where all of the parents in the household reported being in the labor force during the week before the survey. For children living in single-parent families, this means that the resident parent was in the labor force; for children living in married-couple families, this means that both parents were in the labor force.

Based on this definition, the need for child care is lower in Puerto Rico than it is in the United States. However, it is not clear from these census data whether the need for child care is low because women are not entering the labor force or whether women are not motivated to seek work because there are so few child care options available to them. In addition, it is likely that some women who are "not in the labor force" are working in the informal sector, providing domestic services or involved in other work outside of the formal labor force. Puerto Rico has a relatively large informal or underground economy, consisting mainly of self-employed workers--especially women. The informal sector includes many domestic services (cooking, cleaning, sewing) as well as more formal services, such as catering and child care services.

In Puerto Rico, 40 percent of children under age 6 lived in families where all of the resident parents were in the labor force in 2000, compared with 59 percent in the United States as a whole, and 69 percent in the U.S. Virgin Islands. The relatively low percentage of children in need of child care is associated with the low percentage of women who are in the labor force. In Puerto Rico, about one-third (34 percent) of women ages 16 and over were in the labor force in 2000, compared with 58 percent in the United States as a whole.

In Puerto Rico, as elsewhere, it is common for grandparents to provide child care while parents are working, and in many households, grandparents are the primary caregivers for young children. For the 2000 Census, the U.S. Census Bureau added a new question to measure the extent to which grandparents provided care to their grandchildren. In Puerto Rico, there were 133,881 grandparents who lived with their grandchildren in 2000, and about 53 percent reported that they were "responsible for most of the basic needs" of one or more of their co-resident grandchildren. This shows the importance of extended family members--particularly grandparents--as caregivers in the

Commonwealth. In the United States, only 42 percent of grandparents who lived with their grandchildren reported being responsible for their care. (Reference: Children in PR: Results from 2000 Census. Kids Count, Annie E. Casey Foundation and the Population Reference Bureau, August 2003).

## Summary

There was an increase of 7.5% in the total population reported in 2000 as compared to 1990. Nearly fifty-two percent (51.9%) of the population was comprised of females and 48.1% of males. The segment of children and adolescents between 0-19 years of age represented 32% of the total. The MCH population comprised by children and adolescents (0-19 years) and women 20-44 years of age surpassed fifty percent (50.5%) of the total population in the Island. On the other hand, the proportion of persons over 65 years of age reached 11.2% (425,137). The median age was 32.1 years, compared to 28.4 in 1990. The average family size was 3.1 persons. The population of female householders with no husband present was 21.3% compared to 23% in 1990. Among this group, 49% (131,854) of them had children less than 18 years of age under their custody.

According to the 2000 Census, the economic profile of individuals and families significantly improved during the last decade. The level of poverty declined from 58.9% to 48.2%, and the number of families under the poverty threshold leveled off from 55.3% to 44.6%.

The per capita income increased from \$4,177 to \$6,809 (63%). The mean income by household increased from \$8,695 to \$11,989 (34.9%) and the individual mean income grew from \$5,721 to \$10,403; an increase of 81.8%.

A variable not investigated in 1990 is one related with grandparents living with children under 18 years of age. A total of 133,881 grandparents lived in the same household with children under 18 years old. Among these, 52.5% were the main provider for their grandchildren. This situation should be studied in order to understand the reasons and the implications for children and grandparents.

Other indicators of the PR's economic profile are the unemployment rate, number of participants in the Nutritional Assistance and TANF programs, and the number of individuals holding the GIP. As mentioned elsewhere, in 2000 the Census Bureau reported 3,808,610 persons and 1,261,325 families residing in the Island.

The unemployment rate increased from 10.5% in February 2000 to 13.7% in February 2002. This represents an increase of 23.4%. Among adolescents and young adults unemployment is even higher, creating a fertile environment for criminal activities and other social problems. It is important to underscore, that in spite of the upward trend in the unemployment rate, there is a downward trend in the number of families and persons participants of the Food Stamp and TANF programs.

In FY 2004-2005, the average number of beneficiaries participating of the Nutritional Assistance program on any given month was 1,047,267 persons and 457,618 families. These figures represent 25.7% and 36.3% of all individuals and families in PR as reported by the 2000 Census Bureau. It is important to highlight that in 1992, the total number of participants of the Food Stamp program was 1,480,457. A decline of 29% is observed in the number of the participants of Food Stamp program in spite of the increase in the population during a period of 13 years.

In 1998-99, there were 76,146 families and 153,427 individuals enrolled the TANF program. During current year (2004-05), the number of participant families declined to an average of 56,680 and 85,110 persons per month. These figures tell us that the number of participant families in the TANF program has decreased by 27.5% in a 6-year's period. Among all families 15,930 of them have children under 18 years old for a total of 30,977. It is unclear if delinked families and individuals from the TANF program are self-sufficient or simply it is the result to be in compliance with administrative procedures required by federal mandates.

These downward trends in the number of families and persons participants of the Food Stamp and

TANF programs would be the results of the implementation of the PR Welfare Reform Act (PRWORA) and not necessarily it reflects an improvement of the socioeconomic status of the population.

Race and Ethnicity: The 2000 Census was the first census in Puerto Rico since 1950 to include questions about race or ethnicity. For people in Puerto Rico, as well as Hispanics/Latinos living in the United States, "race is a flexible concept". This is evident in a comparison of race responses between people living in Puerto Rico and Puerto Ricans living in the United States. Although the groups share the same heritage, they have very different ideas about racial identity. About 81 percent of people in Puerto Rico identified themselves as white in the 2000 Census, but Puerto Ricans residing in the United States were almost equally likely to say they were white (46 percent) as "some other race" (47 percent).

The most significant ethnic groups residing on the Island are Dominicans and Cubans. Most Dominicans are concentrated in the metropolitan areas close to San Juan. A significant number of Dominicans are undocumented. In 1998, the U.S. Immigration Agency reported 7,540 new lawful permanent residents' aliens and approximately 37,700 illegal residents in the Island. Puerto Ricans, Dominicans and Cubans have a Hispanic background. Spanish is the official language of the Government of Puerto Rico. In addition, a significant proportion of Puerto Ricans can also communicate in English quite well.

The 2000 Census revealed the following ethnic composition in PR: 95.1% Puerto Ricans, 0.5% Cubans, 0.3% Mexican and 2.8% other Hispanic or Latino. Only 0.2% were Asian, Native Hawaiian and other Pacific Islander. Interestingly, according to the Census, 84 percent of the population residing in the Island was White, 10.9% Black and 9.6% some other race.

#### Vital Events 2003

Births: Figure III-3 depicts the vital events registered in PR in 2003. In 2003, the estimated population was 3,878,531. A total of 50,803 live births were registered; 99.9% occurred in hospitals. Only 63 (.1%) live births occurred at home and other places. The natality rate was 13.1/1,000 inhabitants as compared to 18.9/1,000 in 1990. These figures represent a decline of 30.7% in the crude natality rate in PR. On the other hand, the C/S rate was 46%.

Marriages and Divorces: The rate of marriages was 6.6/1,000 inhabitants and divorces occurred at a rate of 3.8/1,000 inhabitants.

General Mortality: Total deaths amounted to 28,356, a rate 7.3/1,000 persons. The ten leading causes of death were: (1) Heart Diseases; (2) Cancer; (3) Diabetes; (4) Hypertension; (5) Chronic Pulmonary Diseases; (6) Alzheimer; (7) All Accidents; (8) Pneumonia and Influenza; (9) Cardiovascular Diseases; and (10) Nephritis and Nephrosis.

Infant Mortality: Figure III-4 illustrates the downward tendency of the infant mortality rate (IMR) in PR from 1990 to 2000. During a ten-year period the IMR declined 26.1%. However, from 2000 to 2003 it has dropped only 1.1%; from 9.9 to 9.8 per thousand live births.

#### **B. AGENCY CAPACITY**

The health care delivery environment has been evolving during the last decade in the Commonwealth of PR as a result of the implementation of a Health Care Reform (HCR). Therefore, an understanding of the changes that are occurring in the Health Care System (HCS) of PR is important to providing the context of the MCH/CSHCN programs priorities and activities.

In this section we pretend to provide the reviewers of this application a synopsis of the traditional HCS of the Commonwealth of PR; and the reasons behind its reformation into a privatized managed care model of health services.

Traditionally, the HCS in PR was divided into two parallel systems, public and private sectors. The public sector was responsible for addressing all health care needs for almost 60% of the population with low-income or uninsured. On the other hand, the private sector served 42% of the population who could paid out of pocket or through third party payers.

The PRDoH historically functioned as the predominant provider of personal health services for low-income and uninsured populations. It operated through an extensive regionalized network of level one primary health care centers, at least one in each municipality; areas' hospitals (level II); regional hospitals (level III); and a Supratertiary Center, located at the PR Medical Center. However, in spite of this extraordinary network of facilities the PRDoH had to place restrictions on the scope of services available and compliance with the schedule of preventive services for low-income and uninsured populations. The HCS had a chronic limitation of trained health care providers and ancillary services such as laboratories, X-rays and pharmacy services, due to insufficient allocation of funds. There were both limited allocation of funds from the Commonwealth revenue and due to the cap in the Medicaid funds imposed to PR as well to other territories. Another limitation was that patients, who could paid for their services did not come to our system, except those with catastrophic illness referred by their physicians.

Over the years, PR's Medicaid program only paid for hospital-based services, including in-patient and outpatient care for categorically and medically needy persons. Because of this, Title V funds were used as the first payor for ambulatory care services for women in their reproductive age (family planning, prenatal and postpartum services), preventive services for children and specialized for CSHCN.

As earlier mentioned, the traditional HCS had primary health care facilities at each one of the municipalities. This was the portal of entry into the HCS for the low-income and uninsured MCH population groups. However, the reality was that primary centers were very under staff. In addition, the majority of the primary providers for women in their reproductive age, infants and children were general physicians who were untrained to address the needs of the high proportion of the at risk MCH population. Besides, they were insufficient in number to serve all the population of the municipality in need of services, including emergency services.

High-risk pregnant women and children were referred to Regional Hospitals for follow-up. Most of the times this was worse for the patient because of the distance they had to travel from their residency to the Regional Hospital for an appointment. As an example, a high-risk pregnant women living in Orocovis had to travel about 38 miles (one trip) in public transportation to reach the high-risk prenatal clinic based at the Bayamon Regional Hospital. In addition, due to the limitation of staff at Regional Hospitals and the high number of referrals the follow-up was not given according to the patient's condition. Other reasons for referrals to Regional Hospital were for laboratory and X-rays services. Children with special conditions ran the same luck as their mothers.

On the other hand, the segment of the population with private insurance or who could pay out of pocket (42%) had a private health care system with access to primary providers, specialists, laboratories, x-rays services, pharmacies and in hospital services at their community level or the nearest municipality to their residency.

In pursuing to eliminate or reduce the disparities in the accessibility and quality of health services provided to the low-income and uninsured population (+ 60%), an aggressive HCR was launched in PR about one decade ago. The HCR driving values are justice and equity for the low-income population in addressing their health services needs. The HCR is an initiative comprised by three main components. These include, (1) a Government Insurance Plan; (2) renting or selling its public health facilities; and (3) enhancing its role in performing the core functions of public health (assessment, policy development and assurance).

The HCR is mandated by Law No. 72 enacted on September 7, 1993. The HCR attempts to bridge

the gaps in services between the public and private sectors through a Government Insurance Plan (GIP). At the same time, one of its goals was to privatize the public health care system through renting or selling its facilities. In addition, the DoH is expected to enhance its role in performing the core functions of public health following the recommendations of the State and Territorial Health Officials (ASTHO): assessment, policy development and assurance. As a result of the implementation of the HCR, the DoH instituted as its top priority the promotion and protection of health.

The initiative of the HCR was based in several basic principles. These are to:

- 1. Eliminate the public and private sector disparity and discrimination in health care;
- 2. Guarantee access to quality health care to all residents;
- Have freedom for selection of a primary health care provider;
- 4. Increase the efficiency and productivity of the health care industry through a competitive mechanisms;
- 5. Improve the quality of services;
- 6. Modify the role of the government in the areas of health promotion, and disease prevention; since participants have the option of selecting the health care site and provider. These principles enhance and guarantee universal access to adequate health care services.

Who benefits from the Government Insurance Plan?

- \* Medicaid Beneficiaries up to 200%
- \* Veterans (Non-Service Connected)
- \* Medicare Beneficiaries (Part A and B)
- \* Police Officers and their families
- \* Public Employees and their direct dependents.

The GIP has three primary objectives. These are: (1) Universal coverage; (2) Freedom of choice; and (3) Expanded benefit package.

The privatization effort is administered by a nonprofit corporation called the "Administracion of Servicios de Salud" (ASES, Spanish acronym). This organization was created in 1993 under PR Law 72 and is responsible for a number of critical administrative activities, including:

- \* Negotiating contracts. ASES is responsible for negotiating and awarding contracts to private insurers to provide services included in the ASES standard benefit package on either a fully- or partially-capitated basis through managed care systems.
- \* Conducting quality assurance. ASES monitors managed care plans by requiring the monthly submission of service utilization data. Reimbursement of the health plans is contingent upon the submission of these reports. In addition, ASES is bolstering its monitoring activities through contracts with a number of organizations; a Peer Review Organization (PRO) is assessing the quality of ambulatory care services, PRDoH is monitoring hospital service quality, and other groups are monitoring regional activities.
- \* Facilitating enrollment. ASES is responsible for enrolling eligible persons into the new system and coordinates eligibility determination activities with PRDoH. PRDoH Medicaid certification staff stationed at primary care centers determine which clients are eligible for the program and forward this information to ASES. ASES, in turn, provides contracted insurers with the names and addresses of eligible persons so that they can send them letters informing them of their eligibility and inviting them to enroll with a managed care provider in their community. Each enrollee receives a health insurance card which gives him or her access to health care services.

In February 1994, the Commonwealth of PR began the implementation of the aggressive HCR initiative mandated by Law 72, 2003. This led to the replacement of the extensive public health infrastructure that traditionally served low-income and uninsured residents in Puerto Rico. The public health service delivery system was incrementally privatized by June 2000. Under this reformed

system, responsibility for providing personal health services to low-income and uninsured populations holding the GIP was transferred from the DoH to the private sector. Currently, all care is delivered through a managed care service delivery model.

The second component of the privatization process was the sale of the public health facilities. The Government had to amend State Law 31, which expedites and facilitates the sale of government owned DTC's and hospitals. The facilities were sold to private for profit and nonprofit organizations. The first request for proposal was announced in May 1997. As of June 2000, the DoH had sold 50 health facilities, including 8 hospitals. Other 10 facilities were rented or administered by the DoH. This component of the HCR was discontinued in 2001.

After the completion of the implementation of the GIP in July 2000, several laws and changes have been established. These include, but are not limited to:

- \* Enactment of Law No. 194, August 2000. This law requires the establishment of an agency to advocate for the rights of patients holding the GIP.
- \* Enactment of Law 408 of 2000. The PRDH is retaking the primary responsibility for the provision and coordination of mental health services for the population enrolled in the GIP.
- \* Pilot project for the implementation of the Intelligent Card. This is an electronic card which contains sociodemographic data, relevant information regarding the health history of the patient, medications and other information.
- \* Establishment of 14 Clinical Guidelines including Perinatal Services, EPSDT, Guidelines for the management of pediatric patients with asthma and diabetes.
- \* The Department of Health assumed the primary responsibility for immunization services after June 2002.
- \* Increase the length of the contract between ASES and the Health Insurance Company to at least 3 years. The three health insurance companies that are providing the services for the population with the GIP are MCS, Triple S and Humana.

Other changes under consideration are to: 1) Readjust the HCR areas to traditional Health Insurance regions; and 2) Contract directly with HMO providers. In July 19, 2002, Law No. 105 empowered Puerto Rico Health Insurance Administration (PRHIA) to conduct demonstration projects of contracting directly with providers, without intermediaries such as managed care organizations. The Demonstration Project began operations on July 1, 2003 with Alianza de Medicos del Sureste, Inc. (AMSE) as a sole provider assuming risks under the basic coverage. A second contract was negotiated with the Family Medicine Group on March 1, 2004. For this second group the Division of Education and Social Communication of the Secretariat for Health Promotion of the Department of Health provides prevention and education services under contract.

The PRHIA is also implementing what is called the "intelligent card", a pocket size card with a microchip that stores the subscriber's medical history including: personal data, diagnosis and medications, last five physician, hospital and emergency room visits, immunization history and more. As of April 2004 a total of sixteen thousand intelligent cards (16,000) had been distributed in the municipalities of Bayamon (4,000), Isabela (7,000) and Vieques (5,000). This is an initiative toward better access and quality of services since it offers electronic retrieval of all the necessary medical information to providers. The 1.5 plus million health care reform patients in Puerto Rico will eventually have an intelligent card. As of December 2004, the total number of beneficiaries was 1,521,981. Among these, 55.16% were WCBA, infants, children and adolescents.

Satisfaction with the GIP: Studies and surveys conducted by the "Administracion de Seguros de Salud de Puerto Rico" (ASES) or the Puerto Rico Health Insurance Administration, show a high

percentage of satisfaction among the clientele. Close to nine out of 10 (87.8%) of those interviewed reported being satisfied with the new service system. This finding is encouraging, because it is the best index of the success of HCR as a social justice project.

Among the reasons given by beneficiaries to preferring the new system in contrast to the traditional system are:

- 1. The Government Insurance Plan (GIP) is better than the services we had before.
- 2. The availability of more and better services.
- 3. There is more accessibility to medications and better pharmacy services.
- 4. There is better attention at the health service centers.
- 5. Services are free or require low co-payment.

The third component of the HCR is the transformation of the Department of Health from a diseaseoriented agency to one that encourages health promotion and protection programs and primary, secondary and tertiary prevention programs within the context of a comprehensive continuum of public health services.

State Health Agency's Current Priorities or Initiatives: In addition to the GIP, which is mainly implemented by ASES, and as a result of the HCR, the Department of Health has modified its role and approaches in pursuing the optimal health of the population. The Department of Health has been emphasizing in the core functions of public health that include needs assessment, policy development and assurance. It has also modified its role of a disease-oriented agency towards one of health promotion, disease prevention and health protection of the population at large.

A Strategic Action Plan has been developed which is divided into three major phases: planning, implementation and evaluation. A variety of initiatives or programs have already been implemented to address the health needs of the population at large or to segments of the population with special needs. These initiatives include, but are not limited to:

- \* The Healthy Community Division of the Secretariat for Health Promotion The mission of the program is to promote healthy lifestyles and behaviors of the diverse population groups in order to decrease mortality and morbidity due to chronic health conditions. The strategy to develop this concept and reach its goal involves a comprehensive health risk appraisal as well as an assessment of the needs and capacities of the participating communities. Challenges and opportunities to improve the health of the community are identified. Beginning with the mayor of the municipality, all community leaders are brought to the table to design a concerted action plan to address identified health needs. The Healthy Community Division has been implemented in 16 municipalities. In each of these Healthy Communities several health promotion and disease prevention programs are implemented in response to its specific needs and the available resources.
- \* The Behavioral Risk Factors Survey, which is a national CDC-sponsored cross-sectional yearly study designed to identify health trends, lifestyles and behaviors among Puerto Ricans. Four questions addressed to identifying asthma morbidity were added this year.
- \* The HIV Prevention Needs Assessment, an Islandwide study of a large sample of high-risk populations. The purpose of the study is to identify the health needs of these groups. The results are used to design custom-made HIV/AIDS/STD primary and secondary prevention programs.
- \* The Basic Sample Survey -This is an annual representative probabilistic survey of approximately 3,000 personal interviews that looks for sociodemographic characteristics, service utilization, prevalence of health conditions and the reasons for work absenteeism, including hospitalization and ambulatory conditions.

Among the programs that contribute to address specific MCH needs are:

- \* The Distance Learning (An Interactive Education program) To educate and train private and public health professionals through nine transmission centers located at regional hospitals Islandwide by means of telecommunications.
- \* Rape Victim Centers The opening of four centers to assist rape victims ("Centro de Ayuda a Victimas de Violacion") and the expansion of services to assist domestic violence victims across the Island.
- \* The Oral Health Prevention Program Under the Health Care Reform, oral health services are included in the benefit package. Patients are not required to obtain a referral to get oral health services. They can access oral health whenever they want and with their preferred dentist. In addition, the Division for Oral Health has a very active prevention program throughout the Island.
- \* The Immunization Program The Puerto Rico Government established compliance with the Hepatitis B vaccination as a requirement for school admission, for those born from 1991 on, and those who are 13 years of age. Since 2000, all adolescents from 13 to 18 must be immunized against Hepatitis B. Puerto Rico has achieved high immunization rate in children through 2 years. Puerto Rico had been the jurisdiction with the highest percent of immunized children in the nation for three consecutive years. However, a marked decline in the proportion of immunized children 24 month old was observed as a result of the vaccine shortage occurred in the nation in 2002. Currently, we have achieved again levels over 90% of immunized children.

The Welfare Reform: We understand that the Welfare reform has not negatively affected the access to health care services of the low-income population. As mentioned elsewhere, one of the three components of the initiative of the HCR consists of a GIP for persons under 200% of the FPL. The GIP is paid mostly with state funds (84.7%). Medicaid funds represent only 12.1% of the total budget used to buy the GIP in PR. Over 1.5 million persons hold the GIP. This figure represents almost 40% of the total population residing in PR.

Puerto Rico CHIP Program: The PR CHIP plan was approved in June 1998. It started with an allocation of 9.8 millions. In 2004-2005, a total amount of 42.3 millions were used to contribute to buy a GIP for children who qualify for the CHIP program. It is estimated that the CHIP monies may be used to pay the GIP of about 50,000 children; considering the current annual premium of \$862.00 per person.

The total population holding the GIP is 1,521,981. This figure includes 383,438 women in their reproductive age and 455,497 children aged 1-19 years. As of September 2004, the network of health care providers available to serve the low income population was the following: 410 OB/GYN's, 570 pediatricians, 210 family physicians, 1,062 GP's, 410 internists and 1,289 dentists.

Current MCH Priorities and Initiatives: As already described, in 1994, the Government of Puerto Rico began implementing an aggressive HCR, under which the public service delivery system was incrementally privatized in all the island's health regions. Under the reformed system, responsibility for providing personal health services to low income and underinsured populations was transferred from the public to the private sector and all care is delivered through managed care service delivery models. The Reform was first implemented in the sub-region of Fajardo and moved very quickly to other areas. Currently, the HCR is implemented Islandwide.

The reformed system replaced an extensive public health infrastructure that traditionally served low income and uninsured residents of Puerto Rico. The PRDH historically functioned as the predominant provider of personal health services for these populations, operating an extensive network of primary care diagnostic and treatment centers (86) and hospitals (9) reaching all corners of the Island.

The PRDH delegated the provision of direct care services to the private sector, through contracts with health insurers, while maintaining the non-delegable core functions of public health. These functions include needs assessment, policy development, assurance and training of health professionals. The

Department of Health also retained the administration of certain federal programs and special services such as the WIC program, Medicaid, services for persons with AIDS and the MCH program, among others.

Considering the above context and the mandates of Title V, the MCH role was refocused to assure, at this time of transition, that the most vulnerable population does not fall through the cracks of the evolving system. The MCH struggles to enable women, infants, children, adolescents and CSHCN to receive high quality and comprehensive services across a system that is now more complicated. Responding to this need, two (2) new core programs were designed and incrementally implemented across the Island. One is the Home Visiting Program that serves pregnant women and children less than 2 years of age with multiple social and health risk factors through a case management care/coordination model. The other one is the Community Outreach program. Community outreach workers' main responsibilities are to identify pregnant women and children delinked from the HCS and to facilitate their enrollment into the GIP, coordinate interagency services and give follow-up to certain situations of the Home Visiting program's clients.

Most important, as an aftermath of the delegation of the provision of direct services to the private sector, has enabled the MCH/CSHCN programs to dedicate more time and resources to the development and implementation of infrastructure building activities. These activities include creating partnerships, monitoring and evaluation, empowering communities, promoting healthy behaviors, building capacity, and advocating for supporting policies. Among these infrastructure building activities it is important to highlight the followings:

- Healthy Start Consortium / MCH Advisory Board: It is a multidisciplinary and intersectorial group of professionals and representatives of the MCH population. They are very committed and knowledgeable of MCH issues. The Advisory Board has been a fundamental piece in providing input regarding new priorities and strategies to address the needs of the MCH population within the emerging new health care environment. Most of their recommended strategies are integrated in the action plan aimed at improving the health and well being of the MCH population including CSHCN.
- Breastfeeding Steering Committee: This committee is comprised by a wide array of stakeholders committed with the promotion of this important behavior aimed at enhancing the growth and development of children.
- Puerto Rico's Safe Kids Coalition: This is a non-profit multisectorial organization. Its goal is to reduce unintentional injuries among children and adolescents.
- Asthma Coalition: The Asthma Coalition was incorporated as an organization comprised by public organizations, private entities, academia and parents. Its goal is to reduce morbimortality rates due to asthma. The coalition holds monthly meetings.
- Title V Monitoring and Evaluation Section: This section monitors all national and state performance measures, evaluate outcome measures and support the MCH needs assessment process. It entails several ongoing activities such as the implementation of the SSDI action plan; a customized PRAMS of recent mothers conducted every other year; an Infant Mortality Epidemiologic Surveillance System (SIVEMI, Spanish acronym); a Maternal Mortality Surveillance System; Integrated Index of MCH status by Municipality; one State SSDI Conference every other year and special applied studies aimed at increasing the knowledge on selected MCH problems.
- Birth Defect Registry: Currently this registry monitor the prevalence of 13 categories of birth defects; NTD's, cleft lip/palate, Down Syndrome, gastroschisis, limb defects, ambiguous genitalia, Trisomy 13, 18, albinisms, congenital heart defects and others.
- PININES (Proyecto de Identificacion de Niños con Necesidades Especiales de Salud, Spanish acronym): Puerto Rico, as well other jurisdictions is not included in the SLAITS. However, we are not waived regarding the responsibility to gather the information to monitor the progress on performance

measures that use the data collected through the SLAITS. Toward this aim we designed the PININES. This is a collaborative effort with the Medicaid Program. The certification instrument used by the Medicaid Program was modified with the assistance of the MCH/CSHCN programs to collect information about 13 common conditions among CSHCN in PR. PININES enable us to have an idea of the most common chronic conditions among children enrolled in Medicaid.

- Folic Acid Campaign: This is a long-range collaborative campaign, which includes a broad array of organizations, private and public agencies. This campaign has been very successful in decreasing the rate of infants born in the Island with neural tube defects. In fact, the National Birth Defects Prevention Network honored PR with the Birth Defects Education and Prevention Award for 2004. This award was in recognition of the outstanding activities of an agency to promote public awareness of birth defects through innovative and collaborative education and prevention efforts.
- Universal Newborn Hearing Screening Program (UNHSP): This program is in the process of implementing newborn hearing screening at all birthing institutions. The program has among its strategies an Advisory Community to help in the implementation process. Legislation has been passed to support the UNHS in PR.
- Emergency Medical Services System for Children, Program for the prevention of pediatric emergencies: This program was developed and implemented in the University Pediatric Hospital with the support of the MCH program. A Law was approved aimed at the sustainability of the program through the recurrent allocation of \$100,000 from state funds.

In closing up this section, it is imperative to underscore that in PR we have a health care system in which the three sectors that affect the health decision --making are there. These are the:

- Informal sector based at the community level, consisting of individuals, families and concerned groups organized to promote specific health issues.
- Formal health care system consisting of network of health providers, organizations, public and private health institutions, and different levels of care that provide preventive and curative services.
- Intersectorial sector comprised by other public, private and non-governmental entities that indirectly influence health.

However, in spite of the above, this health care system has been inefficient in achieving its goal of enhancing the optimal health of all subgroups of the population. This is so because of its fragmentation and the lack of a well designed Health Management Information System (HMIS). A HMIS is necessary for the proper communication among all the parts comprising the HCS. Without it, managers are unable to manage their programs based on reliable data that may be transformed into the information needed for selecting the most appropriate interventions.

Toward this aim, the MCH program established the Monitoring and Evaluation Section of Title V described elsewhere. The current administration nominated a Health Commission to evaluate the HCR initiative. Last June both MCH/CSHCN directors participated in a public hearing conducted by a subcommittee which is evaluating the health promotion and preventive components under the HCR. The MCH Director emphasized the impact of the GIP on goals and objectives set for the MCH population. We understand that major changes in the implementation of the HCR will result from the findings of this Commission.

#### C. ORGANIZATIONAL STRUCTURE

The Puerto Rico Department of Health (PRDoH) is the umbrella agency assigned in Article IV, Section 6 of the Constitution of the Government of PR responsible for all matters pertaining to public health, with the exception of maritime quarantine. The Secretary of Health is appointed by the Governor of Puerto Rico and confirmed by the Legislature.

The Administrative Order No. 179, signed by the Secretary of Health on January 15, 2003, determines the current organizational structure of the Agency (Appendix 1). It comprises 6 secretariats, 12 offices and programs and 6 administrations, the General Council of Health and the Corporation of the Cardiovascular Center of PR and the Caribbean, all responding directly to the Secretary of Health, as well as three offices which respond to the Sub-Secretary of Health.

#### A. Assistant Secretariats:

- 1. Secretariat for Planning and Development
- 2. Secretariat for Regulation and Certification of Health Facilities
- 3. Secretariat for the Prevention and Control of Diseases (ASPCD)
- 4. Secretariat for Health Promotion
- 5. Secretariat for Health Protection
- 6. Secretariat for Administration

## B. Offices and Programs:

- 1. Office of the Secretary of Health
- 2. Office of Internal Audit
- 3. Office of Communications and Public Affairs
- 4. Office of Legal Affairs
- 5. Office of Informatics and Technologic Advances (OITA)
- 6. Office of Human Resources and Labor Relations
- 7. Office of Budget and Finances
- 8. Office of Catastrophic Funds
- 9. Office of PR for Coordination with PAHO-WHO
- 10. Office for the Administration of HIPAA Law
- 11. Office of External Affairs
- 12. Correctional Health Program
- C. There are six (6) independent agencies, administrations, councils and commissions created by law under the umbrella of the DoH. These are the following:
- 1. Administration of Mental Health and Anti-Addiction Services: Law 67 enacted in August 1993.
- 2. Administration of Medical Services: Law 66 enacted in June 1978.
- 3. Corporation of the Cardiovascular Center of PR and the Caribbean: Law 51, June 1986.
- 4. General Council of Health: Law 23, June 1976.
- 5. Commission for the Prevention of Suicide: Law 227, August 1999.
- 6. Commission of Food and Nutrition: Law 10, January 8, 1999.

There are three (3) offices and programs that have been delegated under the supervision of the Sub-Secretary of Health. These are the following:

- 1. Office for Regulation and Certification of Health Professionals
- 2. Regional Health Coordinators
- 3. Office of Nursing Affairs

The current Administrative Order establishes the vision, mission, goals, organizational structure and core functions of its components under the umbrella of the DoH.

The goals of the DoH are to:

- \* Increase years of productive healthy life of all residents in PR:
- \* Reduce health disparities among residents in the Island; and
- \* Achieve access to preventive health services for all.

The DoH places special emphasis in health promotion, prevention and control of diseases, and protection of health. (3Ps)

The ASPCD is responsible for the development and implementation of strategies and activities geared toward the identification of risk factors contributing to poor health among all individuals. It is also charged with the development and implementation of needed programs aimed at the reduction or elimination of such risk factors and the prevention of diseases. Its approach is based on primary interventions at the community level and with special populations.

The ASPCD is comprised of a number of divisions and programs which address a wide scope of health needs of the different MCH population groups. These include the Division of MCH, Division of Habilitative Services, Division of Preventive Health, Central Office for AIDS Affairs and STD's, Mental Retardation Program, Division of Oral Health, Rape Victim Center and the WIC Program.

The PR Title V program is comprised of the MCH and CSHCN divisions, which are within the organizational structure of the ASPCD. Its directors work collaboratively and in coordination promoting the development of systems of care for all women and children and the provision of direct, supportive population-based and infrastructure building services. The goal is to decrease maternal-infant and pediatric mortality in PR. Each division is integrated by several programs, projects and activities supported by Title V funds and other federal initiatives.

Before the implementation of the HCR, PR's MCH program played many different roles in serving mothers and children, including providing direct services, administrating population-based programs and assuming responsibility for core public health functions.

With the advent of the HCR and aided by the recommendations of a TA supported by Region II in 1995 (Health Systems Research, Inc.), the MCH services were refocused. Title V resources were directed toward filling the gaps in direct services not covered by the GIP, development and implementation of support programs for at-risk mothers and children, development of population based programs, infrastructure building services, such as conducting activities aimed at improving the integration of the public and private systems of health care, needs assessment, applied research, development of surveillance systems, interagency coordination of related services, professional development, public education, etc.

Since these divisions and programs are under the same leadership, the collaboration, cooperation and coordination of services among the central, regional and local staff is facilitated.

#### D. OTHER MCH CAPACITY

#### MCH PROGRAM

Some of the current projects, programs and activities based on the MCH pyramid of services are:

Direct Services: We fill in the gaps in services needed by WCBA and CSHCN that are not in the GIP package, including contraceptive methods and Rhogam immunization in the 3rd trimester. Over 40,000 women obtain contraceptive methods and 1,500 receive Rhogam per year.

Enabling Services: Family support services for at-risk pregnant, postpartum women and children up to 2 years of age.

- Home Visiting/Healthy Start Program: An enabling, family-centered, community-based service provided by specially trained public health nurses to pregnant/postpartum women and children up to 2 years of age with medical and social risk factors. The Home Visiting Nurses (HVNs) conduct a comprehensive medical, psychosocial and environmental assessment, develop a tailored

comprehensive care plan in conjunction with the family and coordinate needed services through referrals to the appropriate private or public entity in the community. During follow-up contacts with the family, the HVNs provide health education on a broad array of topics tailored to the family's needs. They conduct formal risk assessment for smoking, alcohol, drug use and maternal depression, providing orientation and referrals according to the level of risk. HVNs promote enrollment of mothers and children in a medical home as well as an interconceptional period of at least 24 months. Most HVNs have been trained to provide counseling on breastfeeding benefits and techniques. As of June 2005, there were 109 HVNs in 74 of the 78 municipalities. The caseload is 45-50 families for a service capacity of nearly 7,000 families per year.

- Perinatal Services: The MCH program has stationed 9 perinatal nurses (PN) at selected institutions that perform a significant number of deliveries. They are also trained in breastfeeding techniques, family planning, distribution of FP methods, and risk assessment of mothers and infants. They provide individual and group education on a variety of topics, make referrals to HVNs and other needed services, collect perinatal data, participate in periodic surveys designed at the central level and are resources for the March of Dimes "Comenzando Bien" prenatal courses.
- Community Outreach: This is another important program developed as a result of the implementation of the HCR. It is staffed by 85 Community Health Workers (CHW) in 63 of the 78 municipalities. Among their main responsibilities are to identify pregnant women and children disconnected from the HCS and facilitate their enrollment into the GIP, coordinate interagency services, give follow up to certain situations of the Home Visiting clients as referred by the HVNs, conduct "Comenzando Bien" courses, provide orientation on MCH topics at the community level, disseminate educational materials, participate in health fairs and data collection, identify problems of access to health services and report to the appropriate level.

Population-Based Services: The MCH program has directed more efforts to developing new population-based programs and enhancing its involvement with those available prior to the advent of the HCR. These include a newborn metabolic/genetic screening program, immunization program, prenatal care outreach, toll-free information line, public education on MCH topics, dissemination of educational materials, folic acid campaign to reduce birth defects, HIV counseling and testing of prenatal patients, AZT administration to HIV positive patients on a voluntary basis, and Universal Newborn Hearing Screening Program (UNHSP).

The Comprehensive Adolescent Health program (SISA, Spanish acronym) integrates all activities directed at reducing adolescent risk factors: pregnancy, unintentional injuries, violence, alcohol and drug use, etc. SISA trains middle school students as peer health promoters and organizes various activities to support them in their work. In collaboration with the Kanopka Institute, SISA is developing a culturally appropriate curriculum on Positive Youth Development and a train-the-trainers guide to promote its application in agencies that serve adolescents.

At the central level SISA is comprised by a multidisciplinary team which includes the Associate Director (a physician with training in public health), a nurse, a social worker, an anthropologist, and a pediatrician with an MPH who coordinates the AEOP work plan. SISA also has 8 regional coordinators under the supervision of the Regional MCH Directors.

The Abstinence Education Only Program (AEOP) is integrated into SISA. Among its strategies are the Sex Can Wait Curriculum, peer groups led by mentor teachers, teacher training, parent workshops, summer camps and dissemination of educational materials.

Infrastructure Building Services: This is an area of enormous development after the HCR. The MCH program has developed a section of programmatic advisors on reproductive health, pediatrics, social work and health education. The nutritionist and nurse coordinators retired last year.

The Title V Monitoring and Evaluation Section is located at this level of service. It is supported by the SSDI project and staffed by an extraordinary group of skilled public health professionals, including a

Demographer who is the SSDI and Section Coordinator, a Biostatistician in charge of the PRAMS-like surveillance, two epidemiologists (master level), one in charge of investigations on reproductive issues and the other on children's health; an Evaluator in charge of the development and implementation of a maternal deaths surveillance system, a Programmer who supports all data infrastructure issues and coordinates with OITA, and the data contact, an Evaluator in charge of the Title V Electronic Monitoring System. He also collaborates with the Title V Director in the needs assessment and monitoring of the Title V action plan, designs instruments to collect qualitative data, and evaluates programs.

- MCH Advisory Body (Healthy Start Consortium): It is comprised of about 50 persons representing public agencies, academia, community organizations, and consumers. They provide input on the selection of MCH priority needs and how to address them, help in the coordination of services across public and non-governmental agencies and are resources for professional development.
- MCH Regional Working Groups (RWGs): These are comprised by members of public and private agencies and consumers. They facilitate coordination of services across agencies and programs and provide recommendations to deal with system problems that interfere with access to services.

Other activities include the development of standards of care, interagency coordination, technical assistance and support of community programs, professional development in the area of MCH, information dissemination to concerned stakeholders, policy development and assurance of care, among others.

The MCH/CSHCN programs possess the technology (computers and statistic software) needed to perform an excellent work.

The MCH Director, a board-certified pediatrician with a master's degree in public health, has occupied different positions at the PRDoH for 28 years. He has been a primary health care provider, director of a pediatric residency program, and director of the MCH program at regional level and holds the present position since December 1990. He was honored as the best student graduated from the MCH program at the 25th anniversary of the School of Public Health. In November 2004, he was the recipient of the 3rd Annual March of Dimes Jonas Salk Public Health Leadership Award.

To furnish the comprehensive array of services recommended by the MCH pyramid, we have 34 FT positions at the central level (Appendix 2) and 8 regional teams, each under the supervision of a Regional MCH Director. These teams are comprised of a coordinator of services for WCBA, coordinator of pediatric services, SISA coordinator, health educator, perinatal nurse and administrative support staff.

At local levels we have at least one HVN and one CHW. As of June 2005, there were 109 HVNs and 85 CHW distributed across the Island. Four municipalities do not have HVNs and 15 lack CHWs.

#### **CSHCN PROGRAM**

Appendix 3 illustrates the organizational structure of the CSHCN program. It is comprised of several projects, programs and activities. These include 7 Regional Pediatric Centers (PCs), Early Intervention program (EIP), Early Childhood Comprehensive System project (ECCSP), NUHSP, Asthma project, Folic Acid Campaign, Congenital Anomalies Registry, PININES and the Surveillance System of Autism Spectrum Disorders.

Direct Services: The CSHCN program provides services to eligible chronically ill and disabled children through its PCs, one rehabilitative hospital, specialty clinics at the University Pediatric Hospital, and 7 Immunology Centers for AIDS patients. Currently, the CSHCN program serves about 15,000 non-duplicated CSHCN per year.

The PCs complement specialized services not covered by the GIP or provided in an insufficient amount. They have been certified as providers of specialized services for the networks of the health

insurance carriers. At these facilities, eligible children receive specialty care, assistive technology, ancillary services, and highly specialized services required by children with metabolic and genetic disorders and mental retardation. Children with AIDS or hemophilia are referred to the appropriate programs. Health insurance carriers are billed for services provided to children holding the GIP or a third party payor. Reimbursement monies revert to the PCs.

Direct services are also provided to pediatric patients with complicated asthma by the Pediatric Pulmonary Program located at the PR Cardiovascular Center. This program is fully supported with Title V funds.

Enabling Services: The CSHCN program provides care coordination services primarily to children with developmental disabilities ages 0-3 who are eligible for the EIP. Nurses have been trained to perform this activity. Case management is conducted collaboratively with the Association of Parents of Children with Disabilities (APNI, Spanish acronym). There are 75 case managers (Service Coordinators) distributed across the Island.

- Catastrophic Illness program. This program, funded 100% by the state, allows access to very expensive services to individuals with catastrophic conditions. A significant proportion of the patients are children under 21 years of age. They are served either in PR or in the mainland. Around 150 children benefit from the program per year, with costs ranging from 6 to over 7 million dollars.

Population-Based Services: The NTD prevention campaign through the promotion of folic acid consumption among WCBA is conducted with the collaboration of many partners and through a broad array of activities including dissemination of educational materials (posters, pamphlets, etc.) in a variety of settings and integration of the message into the health education curriculum beginning in elementary school.

Infrastructure Building Services: At this level the CSHCN has the following projects:

- ECCSP pursuing the development of cross-service systems to support children 0-5 years to be healthy and ready to learn. A State Interagency Planning Committee supports the project.
- UNHSP, in the implementation phase. Currently, 19 hospitals conduct hearing screening regularly.
- Addressing asthma from a public health perspective. The CDC supports this project.
- Congenital Anomalies Registry, supported by CDC, tracks 13 categories of conditions.
- PININES. In collaboration with the Medicaid program, all children are screened for 13 chronic conditions at the time of certification for the GIP.

#### E. STATE AGENCY COORDINATION

The needs of the MCH population are multiple and complex. Because of this, there is no public or private agency, program, or community based organization that can satisfy all the needs of the most vulnerable population comprised of women in their reproductive age, children and adolescents. It is therefore imperative to establish appropriate coordination mechanisms among all concerned entities in order to reduce duplication and fragmentation of services and to be more efficient in the utilization of the scarce resources available.

In Puerto Rico, we have in place fairly satisfactory coordination mechanisms among several public agencies and other sectors of the community at the state, regional and local levels. These coordination mechanisms are at both formal and informal levels. The Department of Health has established formal relationships with other state public agencies, local public health agencies,

academic institutions, federally qualified health centers and tertiary health care facilities. All of these formal arrangements enhance the capacity of the MCH/CSHCN programs.

This formal coordination is the outgrowth of established laws and executive orders of the Governor, which mandate specific agencies and programs to sit at the table to coordinate certain types of services for the MCH population. There are also memorandums of understanding (MOU) among agencies and programs, which enhance the coordination of services. Other formal mechanisms, which contribute to the achievement of this goal, are interagency committees, task forces and coalitions, among others. Several of the laws, executive and administrative orders and committees require the participation of consumers.

At this point, we want to highlight some of the laws, executive orders, MOU and committees that enhance the provision of health services and coordination among all concerned entities, which serve the MCH population. The central staffs of the MCH/CSHCN programs are regular members of most of these arrangements.

## General Public Policy:

- \* Law No. 72 enacted on September 7, 1993 mandated the establishment of a Health Care Reform which includes a GIP for all individuals under 200% of poverty line. Under this law ASES was created. ASES is responsible for negotiating and awarding contracts to private insurers to provide services included in ASES standard benefit packages.
- \* Law No. 194, August 2000: To establish the Patient's Rights and Responsibility.
- \* Law No. 408, October 2000: To establish the needs for prevention, treatment and rehabilitation in mental health, and to create the Bill of Rights of adults and minor patients.

#### Public Policies Concerning Women of Reproductive Age and Infants:

- \* Law No. 84 -- Enacted in 1987. This law mandates the Department of Health to create the Hereditary Diseases Program to detect, diagnose and treat children with Hereditary Diseases. It requires that every infant born alive in PR must be screened for PKU, hypothyroidism and sickle cell anemia. Currently, two other conditions are routinely screened: galactosemia and congenital adrenal hyperplasia. In addition, the Law requires the establishment of the Council for Hereditary Diseases of PR. The council is integrated by four (4) licensed physicians; one (1) representing the Secretary of Health; one (1) parent of an affected child; and one (1) member should represent programs of continued education for health professionals. Among its responsibilities, the council will recommend the type of conditions to be screened and the kind of diagnostic tests to be used by the Program of Hereditary Diseases of PR. This law is under revision of the Legislature in order to increase the number of conditions to be screened.
- \* Law No. 27 -Enacted on July 1992, allows health care professionals to provide prenatal care and postpartum services to minors without parental or guardian consents.
- \* Law No. 70 Enacted on August 1997. It mandates the Secretary of Health to establish a committee charged with the responsibility to develop studies and provide recommendations for the reduction of infant mortality. The law requires an interagency committee including ASES, comprised of nine members under the leadership of the MCH Director.
- \* Administrative Order 129, enacted on July 29, 1998 To establish regulations for all health professionals through continuing education, requiring at least 3 CME credits on the subject of breastfeeding at the time of re-certification. This strategy is aimed at increasing the knowledge and promoting positive attitudes of health providers towards breastfeeding as a means of educating and encouraging breastfeeding in the community. A Steering Committee was organized, consisting of 11 partners from several private and public entities, such as MCH Division of the Department of Health; La Leche League; Department of Education; MCH Health Division of San Juan (Capitol City of Puerto

Rico); WIC Program; LACTA Project; Department of Family Affairs; and community advocates. This committee developed a 5-year plan with the purpose of reaching the year 2010 objectives related to breastfeeding and includes the enforcement of Administrative Order 129 through a collaborative effort with the professional boards regulating the individual health practices. This Order also promotes 24-hour mother and child rooming-in in the hospital setting as a strategy to enhance breastfeeding and the well being of the mother and her infant. The Administrative Order has promoted several laws that protect and enforce the rights of all mothers to breastfeed their babies. These laws have been enacted recently as a result of the continued efforts of this committee as well as other breastfeeding advocates in the community.

- \* Law No. 32 -Enacted on January 10, 1999. To establish areas designed for breastfeeding and change diapers for young children in malls, government centers, ports and airports.
- \* Law No. 427 Enacted on December 2000. To require that working breastfeeding women be allowed 30 minutes per day to express their milk.
- \* Law No. 311 A legislative mandate for newborn hearing screening is in place since December 19, 2003. Coverage for screening and audiological diagnostic testing is required for all health insurance plans in Puerto Rico.
- \* On March 13, 2004, Puerto Rico enacted Law 79 aimed at prohibiting the administration of any breast milk substitute to newborns without the written consent of the mother. Any institution that violates this law will be fined.
- \* Law No. 95, enacted on April 23, 2004, prohibits discrimination against women who breastfeed in any public setting.
- \* Healthy Start Consortium and Advisory Board to the MCH programs. Currently, it is comprised of about 40 members who represent public agencies including the Department of Health, academia, community based organizations, Medicaid, ASES, WIC, consumers, etc.
- \* Committee for the Promotion of Folic Acid Campaign includes the Department of Education & Puerto Rico's chapter of March of Dimes among its members.
- \* Advisory Board of the Midwife Training Program of the School of Public Health The MCH Director is an active member.

Public Policies Concerning Children and Adolescents:

- \* Law No. 25 -- Enacted on September 1983 requires complete immunization as established by the DoH to all preschool, school age children and universitary students at the time of enrollment.
- \* Law No. 259 -Enacted on August 31, 2000. To establish an Emergency Medical Service System for Children Program for the prevention and surveillance of pediatric emergencies. The law assigns \$100,000.00 per year for the implementation of the program. This legislation will allow the sustainability of the EMSC program granted by the federal government.
- \* Law No. 296 Enacted on September 1, 2000. This law mandates a medical evaluation according to EPSDT standards for all children enrolled at day care centers, Head Start programs, and private and public schools on an annual basis.
- \* Administrative Order 158, enacted on September 13, 2000 To establish regulation for training in Comprehensive Adolescent Health.
- \* Law No. 177 enacted on August 1st, 2003: For the comprehensive protection and well being of childhood. It requires coordination (Art. 6) among the Department of the Family, Department of Education, Department of Health, AMSSCA, Housing Department, Justice Department & Police

Department, among others.

- \* PR Safe Kids Coalition Includes public agencies such as DoH, Department of Education, the Police Department, Fire Department and many non-governmental community agencies and individuals.
- \* During 2004, interagency agreements with the Department of Family and the Early Head Start consortiums were revised and updated. Interagency steering committees were implemented for the UNHS and ECCS programs.
- \* Law No. 220 -- Enacted on August 21, 2004 to establish the Bill of Rights for pregnant teens enrolled at public schools.
- \* COPRAN -- It is the Puerto Rican coalition aimed at preventing underage drinking. This aim is pursued through a wide array of activities which include lobbying for appropriate legislation. The MCH program has a formal collaborative agreement with COPRAN.

## Public Policies Concerning CSHCN:

- \* Administrative Order No. 95 The Metropolitan Pediatric Center was integrated to the University Pediatric Hospital to maximize its administrative functions and to better serve the special needs population. Normatively, the Pediatric Center responds to the Division of Habilitative Services.
- \* Law No. 51- This law was enacted on June 7, 1996. It mandates the provision of comprehensive educational services to individuals up to 21 years of age who have special educational needs. The law requires the establishment of an Advisory Council. An outstanding responsibility of the Department of Health under this law is to screen all children born in PR in facilities of the DOH or privatized, for developmental delay during the first three months of age. Identified children will be referred to the Early Intervention Program (EIP) with parental consent for eligibility determination and for provision of services until age 3 years. This strategy will assist the program to increase the number of children identified and enrolled during the first year of age. From ages 3 to 21, the Department of Education is ultimately responsible for providing educational and related services and the required coordination with six other agencies.
- \* Law No. 318 -Approved on December 2003 designates the PRDoH as responsible for developing and implementing public policy for the evaluation, management, and registry of children and adults with autism.
- \* Law No. 351, September 2004: To establish a Birth Defect Registry at the PRDoH. This law requires that all providers and agencies which come in contact with cases of birth defects must report them to the Department of Health regardless of gestational age. The Birth Defects Surveillance System program is responsible for developing protocols for an active surveillance system and to establish a data bank to allow research on contributing risk factors to birth defects. The principal objectives of this law pursue the determination of incidence and prevalence rates of selected births defects in PR, develop prevention strategies, promote early referrals of identified cases to available services and promote the collaboration among the public at large and private partners concerned with this issue.
- \* Advisory Council of Special Education to the Secretary of Education The CSHCN director represents DOH.
- \* State Council on Developmental Disabilities The CSHCN director represents the Secretary of Health.
- \* The PR Asthma Coalition implemented in 2000 to reduce morbimortality due to asthma in Puerto Rico. The Director of Pediatric Pulmonary Program is the president.
- \* Committee of the University Affiliated Program (UAP) -- Includes consumers.

\* United Funds of PR - CSHCN director participates with other representatives of the community.

#### F. HEALTH SYSTEMS CAPACITY INDICATORS

The two main goals of the health services system are to: (1) optimize the health of all segments of the population by employing the most advanced knowledge about health and disease; and (2) minimize the disparities across population subgroups to ensure equal access to health services and the ability to achieve optimum health. (Starfield, 1992)

In 1992, Starfield developed a model for understanding systems functions and for devising approaches to measuring the performance of the health care system. The three components of the functioning of the health care system include structures (inputs), processes and outcomes (outputs). These three components are linked by a system of information necessary to provide a continuous feedback concerning the performance of the health care system. It is important to underscore that the HCS operates within the larger context which includes the social, political, economic and physical environment.

The evaluation of the health system capacity to improve the health of pregnant women, mothers and children, including CSHCN, is most appropriately measured through the analyses of health status indicators than through the use of health status goals.

Toward this aim, the Title V Guidance has identified 11 health systems indicators to be used by all States and Jurisdictions to assess the capacity of the health care system to address the needs of the MCH population. These HSCIs measure the percentage of children financed through Medicaid, CHIP or SSI who have access to specific preventive services. However, as mentioned elsewhere, the allocations of Medicaid and CHIP funds to Puerto Rico are capped. Even worse, Puerto Rico does not receive SSI monies. The amount of Medicaid funds used in Puerto Rico in 2003-2004 to purchase a health insurance plan for the low-income population represented only 12.1% of the total budget designated for this purpose. Similarly, the proportion of CHIP funds was only 3.2%.

Therefore, it will be quite difficult for us to measure the proportion of infants, children and women who receive any specific service paid by means of Medicaid or SCHIP funds. However, we are able to measure the number and proportion of infants, children and women who receive services paid by the GIP. This is understood to be a proxy of what these HSCIs intend to measure.

Adequate health care does not equate maintaining good health status; however, lack of quality health care is a significant contributing factor to poor health status of any of the segments of the population. In this regard, the PR Department of Health is the ultimate responsible for maintaining the health care system, both at the population based-infrastructure as well as individual health care services, such as preventive and primary care.

The infrastructure of the HCS of Puerto Rico includes a variety of components. These are the Department of Health, Health Insurance Administration, health carriers and their network of providers, 19 federally funded primary care centers, community-based organizations and many others. Definitely, the components needed to serve the population are there. On the other hand, nearly 99% of children and adolescents hold a health insurance plan; either government paid or through third party payor. However, the infrastructure of the health care system alone does not have the capacity to appropriately serve the segment of the MCH population comprised by infants, children and adolescents. This is so because in order for a system to achieve its goal, it is necessary to have clear processes (norms and regulations) and excellent data and information systems to connect and communicate each one of its components. This is the Achilles tendon of the PR Health Care System and social accountability needs to be improved in this respect.

Currently, it is possible to determine the number of children and adolescents who have a health insurance plan. But we cannot identify how many children have received appropriate preventive

services through the primary preventive care system comprised by the public-private sectors resulting from the implementation of the HCR initiated in 1994. The identification of persons disjointed from the HCS is not an easy task in the new evolving system.

Similarly, there are no mechanisms for the identification of persons who have been hospitalized during a specific time period for conditions like asthma, diabetes, suicide attempts, etc. PR does not participate in the National Hospital Discharge Surveillance.

Another problem encountered is the lack of mechanisms in place to assure that services are provided according to the current standards of care and the patient's age.

The cornerstone of the health care system is primary care. Primary care is described by several characteristics (Starfield). It is the point of entry into the health care system-first contact. First contact must lead to a continuous, comprehensive and well-coordinated care rendered to all individuals without discrimination of any kind. Health Systems Capacity Indicators are a useful tool to monitor the capacity of the primary care infrastructure to address the needs and maintain the health of the population.

Other important characteristics of primary care are that it should be community-based, family-centered, with the appropriate number of culturally competent providers.

Comprehensiveness requires that the facility has available a range of services needed to address the most common health problems affecting the population at the community level. It is in the area of comprehensiveness that issues related to the provision of all types of services are of concern for both physical and mental health problems, attention to acute conditions, ongoing care for individuals with special health care needs as well as the preventive services to maintain optimal health. Individuals with an identifiable source of primary care (Medical Home, PM #3) are more likely to have chronic conditions (e.g. asthma) that are well controlled than those without a regular source of care.

In PR, over 95% of the overall population holds either the GIP or private insurance paid by a third party. However, this is not translated to expedited accessibility to needed services. The HCS is quite fragmented and the capitated model of care for more than forty percent (42.3%) of the population (low income) does not promote a primary health care system exhibiting the characteristics described earlier.

The capacity of the emerging health care system of PR to address the needs of the MCH population will be commented very briefly using the HSCIs.

#01 HSCI: The rate of children hospitalized for asthma (10,000 children less than 5 years of age).

Children suffering from asthma show higher school absenteeism, are more prone to use the ER services, and more likely to require hospitalizations. Hospitalizations may be an indicator of the level of severity of an asthmatic child, lack of continuity of care or inadequate management of the condition by the primary providers.

Asthma is the most common condition among CSHCN in the Island. We evaluated the most common conditions of 36,498 children enrolled in the Head Start Program in 2004-2005. Of these, 16.7% were asthmatic. The number of pediatric pneumologist is not sufficient to serve children with moderate to severe asthma. In addition, most of them are located at the metropolitan area.

The Pediatric Pulmonary Program located at the PR Medical Center serves the pediatric population of PR with conditions such as asthma, cystic fibrosis, and pulmonary diseases dependent on high technology. The total of patients served by the program during the reporting year was 2,072. Its staff has an active role in the Asthma Coalition of PR. The Director of the Pediatric Pulmonary Center is the president of the Asthma Coalition.

Please refer to State PM No. 7 for the activities that have been planned by the Division of Habilitative Services to address this health problem.

#02 HSCI: The percent of Medicaid enrollees whose age is less than one year who received at least one initial periodic screen.

It is important to highlight that PR is not treated fairly at the time of allocation of Medicaid monies. As a matter of fact, in 2003-2004 Puerto Rico used close to \$1,114.6 (84.7%) million of state and municipal funds to purchase the GIP for low-income persons under 200% of the FPL. Medicaid dollars represented only 12.1% (\$159.2 million) and SCHIP funds 3.2% (\$42.3 million). Since the budget used to purchase the GIP for low-income individuals is a combination of state and local funds (municipal), Medicaid and CHIP, estimates are used to ascertain the number of Medicaid enrollees at any age who have received at least one initial periodic screening during any given period. In 2004-2005, ASES reported that 28,656 infants <1 year received at least one initial periodic screen. This figure represents over 56% of infants under 1 year of age.

Another problem that complicates the monitoring of this HSCI is that the model of health care is based on capitation and providers do not bill the Medicaid program for services rendered, as is the case in the mainland.

#03 HSCI: The percent of SCHIP enrollees whose age is less that one year who received at least one periodic screen.

The data provided by ASES does not identify the number of infants served with SCHIP monies. However, based on the amount of CHIP funds used to paid for the GIP and the primes per person per year; a total 49,082 children 0-18 could be served.

In the case of Head Start children it was found that 79.8% had the GIP compared to 19% a third party payors and 1.3% reported to have no type of health insurance.

#04 HSCI: The percent of women (15 through 44) with a live birth during the reporting year whose observed to expected prenatal visits are greater than or equal to 80% on the Kotelchuck Index.

The MCH Division has a well-trained competent team with the skills for determining the Kotelchuck Index by age groups, municipality of residence, health regions, as well as by many other sociodemographic variables. Indeed, this is one of 15 health indicators that we analyze on a yearly basis to determine the Integrated Index of Maternal and Child Health by municipality (IIMCH). Data generated is widely disseminated to concerned entities and stakeholders responsible for promoting first trimester admission into PNC and the quality of prenatal care.

The percentage of women 15-44 years with a Kotelchuck Index greater or equal to 80% has not changed during the past three (3) years. In 2000 it was 83.1% reaching 83.2% in 2003.

#05 HSCI: Comparison of health system capacity indicator for Medicaid, non-Medicaid, and all MCH population in the state.

In Puerto Rico, the MCH population under 200% of the poverty level is granted the government insurance card. This may be considered a proxy for Medicaid. Information regarding the health plan held by women at the time of delivery is collected in the birth certificate. This allows us to evaluate birth outcomes according to the type of health insurance. In 2003, 63.9% of all live births occurred to women holding of the GIP.

A similar analysis is more difficult for other groups of the MCH population such as children and adolescents. In the case of Head Start children it was found that 79.8% had the GIP compared to 19% a third party payors and 1.3% reported to have no type of health insurance.

#06 HSCI: The percent of poverty level for eligibility in the State Medicaid and SCHIP programs for infants (0-1), children and pregnant women.

The Medicaid program is responsible for developing the criteria for the level of income that a family should have in order to be awarded the GIP. The GIP is the proxy for Medicaid and the level of income is not necessary the same as the FPL. Currently, the established poverty level in PR is 200%.

#07 HSCI: The percent of EPSDT eligible children age 6 through 9 years who have received any dental service during the year.

In 2003-2004, a total of 301,329 children received dental services. These were distributed as follows: 0-5 years (59,781); 6-9 years (87,391); 10-14 years (96,247); 15-19 years (93,830).

All EPSDT eligible children (0-100% FPL) hold the GIP, as well as those in the FPL 101-200%. Both of these groups have direct access to dentists. About 120,890 children aged 6-9 had the GIP which is the proxy for eligible children for EPSDT in PR. Among these ASES reported 87,391 had received any dental service during the year 2003-2004. This figure represents a 72.3% of children who had received dental services.

#08 HSCI: The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the state CSHCN Program.

Puerto Rico does not receive SSI funds. For this reason, we cannot respond to this HSCI.

#09A HSCI: The ability of States to assure that the MCH program and Title V agency have access to policy and program information and data.

In Puerto Rico, the Office of Informatics and Technology Advances (OITA) has the responsibility to develop the data banks of births, deaths and stillbirths files. For a long time, the OITA Director has been a great collaborator of the MCH Program. Close to June of every year he provides us the linked birth and infant death as well as stillbirth banks. Additionally, the OITA Director supports us whenever a technology problem arises.

On the other hand, the MCH program is fortunate to have on staff a very well trained and enthusiastic team of public health professionals to analyze the data contained in the banks provided by OITA. The team consists of a Demographer, who is the Coordinator of the Title V Monitoring and Evaluation Section; two Epidemiologists; two Evaluators, a Biostatistician, a BA in Computer Sciences and a Data Entry Clerk. A pediatrician with an MPH and an OB/GYN consultant with vast experience in public health support this team.

Over the years, the MCH Director has developed the relationships and mechanisms to get the needed information from other programs under the umbrella of the DoH such as WIC, Medicaid, Immunization, Pediatric AIDS, as well as from other programs outside the DoH. Among this last group are the Newborn Screening for Hereditary Diseases, the Department of Education, the Department of the Family and many others.

However, even though the MCH program has the ability to access information and data collected by

other programs and agencies, these may be useless because it is not collected in the form needed by us.

#09B HSCI: The ability of States to determine the percent of adolescents in grades 9 through 12 who report using tobacco products in the past month.

This information is available from the Department of Education whenever they perform the YRBS.

#09C HSCI: The ability of States to determine the percent of children who are obese or overweight.

Obesity and overweight in children is a public health concern in PR. However, we don't know the rate of obesity or overweight in the Island. The information gathered through the YRBS does not answer this question. There is a need to design a study of a representative sample of the population of children and adolescents 0-19 years (N=1,485,004) to determine the percent of children and adolescents who are obese.

Toward this aim the MCH program spearhead a team of partners interested on this issued. The team was comprised by MCH staff, Department of Education, Association of Private Schools, School of Medicine, School of Public Health, Internship of Nutrition and Dietetics, WIC program, the Puerto Rico Chapter of the American Academy of Pediatrics, Puerto Rican Society of Pediatrics, Foundation of the College of Physicians among others. The team decided to start the evaluation of the nutritional status of a representative sample of 2nd grade students enrolled in both public and private school systems. The sample consisted of 3,138 students from 251 schools across the Island.

The methodology included measuring the height and weight to estimate the BMI of participant children. A brochure was designed entitled "Peso Saludable" which contains information and advise on how to maintain a healthy weight.

A total of 60 interviews (a sub sample of the participants children) were conducted to evaluate dietary and physical activity habits in 2nd grade students. The Foundation of the College of Physicians donated 10 scales. On the other hand, the Puerto Rico Academy of Pediatric got 255 stadiometers from the Genetech Company. These donations facilitated conducting this investigation as programmed. It is important to underscore the participation of 100% of schools selected for the study. Currently, we are in the process of analyzing the data collected.

For many years, the MCH program collect morbidity data of Head Start children. Among this preschool children; 10.9% were reported as being obese during 2004-2005.

Next year we will embark in the estimation of the prevalence of obesity and children enrolled in the 7th grade.

In conclusion, low-income pregnant women and children are one of the most vulnerable subgroups of the population in a community. This subgroup of the population requires access to a set of preventive services which include, but are not limited to, prenatal care, an early periodic screening, diagnosis and treatment package of services, dental care and anticipatory guidance according to identified risk factors. On the other hand, CSHCN such as asthmatics require a higher level of services and specialty care to prevent complications requiring ER visits, hospitalizations, and as a result an increased rate of death.

Medicaid, SCHIP and SSI programs are federally financed programs pursuing access to health care services for individuals below the FPL. The implementation of both Medicaid and SCHIP program in PR is very different in comparison with the U.S. mainland. And as a matter of fact, the SSI program has never been implemented in PR, since US citizens living in the Island are not considered at the time of allocation of SSI monies.

#### IV. PRIORITIES, PERFORMANCE AND PROGRAM ACTIVITIES

#### A. BACKGROUND AND OVERVIEW

The PR MCH needs assessment process is a continuous activity carried out on a year round basis. It is aimed at identifying the specific and changing needs of the different MCH population groups. This activity provides the necessary feedback to readjust the MCH work plan to better respond to changes in health needs of the target population. The needs assessment is geared by the H.P. 2010 national objectives related to the MCH population (Focus Areas 9, 16 and others); national and state performance and outcomes measures, as well as the health status indicators established by the MCHB.

Another complementary activity to the needs assessment is the identification of all activities, services and programs according to the MCH pyramid levels for each of the population groups. These two activities allow us to match MCH health needs with available services and to identify gaps in services that should be filled.

Currently, the Title V program has a section staffed with a well-trained team of professionals whose main task is to gather the most accurate and timely data to monitor the progress of all performance and outcomes measures, as well as the level of progress in improving the health and well-being of the Puerto Rican MCH population.

After that, Title V funds are allocated to complement services, to conduct new activities or to implement new programs that will help us to achieve the established target of performance and long terms outcome measures.

The MCH priorities are determined based on the identified needs, the state capacity to address these needs, the political priorities and input from a broad array of partners including families. The trend analysis for at least five years of the rates of each national and negotiated state performance and outcome measures allow us to set expected targets for future years.

Selection of State Priority Needs:

A total of ten (10) priority needs were selected based on data analysis, number of persons affected, input from collaborators, state political priorities, availability of resources to address identified needs and reliable culturally sensitive treatment or management options.

The Puerto Rico MCH work plan is focused on the following priorities:

- 1. Improve maternal health.
- 2. Reduce unintended pregnancies.
- 3. Improve newborn health.
- 4. Reduce adolescent pregnancies.
- 5. Reduce behavioral risk factors among pregnant women and adolescents (smoking, alcohol and substance abuse).
- 6. Reduce unintentional injuries among children and adolescents.
- 7. Increase availability and accessibility to preventive and quality primary health care services for the MCH/CSHCN populations.
- 8. Decrease morbidity and mortality due to bronchial asthma.
- 9. Improve coordination among health care plans, primary physicians and the Pediatric Centers.
- 10. Promote successful transition of youth to adult life.

#### **B. STATE PRIORITIES**

Figure IV-1 depicts the relationship among PR's selected priority needs, its capacity and resource capability, the national and State Negotiated Performance Measures and the long term health

outcomes set for our mothers, children and adolescents (MCA).

Improving the health status, well being and quality of life of the MCA and their families is a great challenge for the MCH/CSHCN programs. To achieve this goal it is imperative to develop and implement a concerted action plan among a diversity of public agencies, private entities, and CBOs, with the involvement of the families themselves. This is so, because the health status and well being of an individual, or a selected population group, results from the intricate interaction of genetic, environmental and sociodemographic factors. Currently, there is not a single public or private entity with all the resources and capability to address by itself the multiple and complex socioeconomic and health needs of the MCA population. This conclusion is drawn from the comprehensive five (5) years needs assessment of the Puerto Rican MCA population. Their needs are diverse and very complex. The five years needs assessment was performed by means of in-depth analysis of quantitative data collected by the Demographic Registry and the Vital Statistic Office as well as other secondary data sources; by gathering primary and qualitative data; conducting applied research and gathering input through the participation of the MCH/CSHCN staff in hundreds of interagency meetings, coalitions, commissions, task forces, committees; and through focus groups of different MCA groups. Sadly, this process led us to realize that there is a wide gap between the current MCA health status and well being, and the expected goals set for 2010. In 2003, the IMR was 9.8/1,000 live births compared to the established goal of 4.5/1,000 by 2010. The MMR was 25.5/100,000 live births in comparison to 3.3/1000 by 2010. This ratio is 7.7 times higher than the established goal.

The contributing (or risk factors) to these poor MCA health outcomes are not only in the realm of medical factors but also in the domain of sociodemographic, environmental and behavioral factors. It is imperative to highlight that in the epidemiology of MCH, there are several independent variables such as heredity, race and ethnicity, income, education, marital status, culture, age groups and area of residence, that are not under the control of the primary role of the MCH/CSHCN programs. Additionally, the contributing factors of the epidemiologic model of the MCH are immense. These include medical risk factors, obstetric complications, behavioral risk factors and the quality of prenatal, perinatal, postpartum and pediatric care, among others. The interrelationship of both, the determinant and contributing factors, leads to short term (<1 year), intermediate (1-5 years) and long term (5-10 years) MCH outcomes. The priority needs for PR were drawn from the analysis of this MCH epidemiological model and the government's political priorities.

Figure IV-1 represents the PR Title V Block Grant Performance System. It shows at a glance the relationship of selected priority needs with current available services to address them by levels of the MCH pyramid. The National and State Negotiated Performance Measure are grouped by the level of the pyramid, which includes the programs, services or activities that, if properly implemented, would result in achieving its set goals across the years. The cumulative achievements of the National and State Performance Measures should lead us to reach the ultimate goal of the Title V Program: "Improving the health and well-being of all women in their reproductive age, infants, children, adolescents and their families". The measures that will tell us how effective our efforts have been over the years are the maternal, infant and child death rates shown at the end of the PR Title V Measurement System.

After the earlier general description, we would like to be more specific describing the relationship among the priority needs with the components of PR Title V BG Performance Measurement System. Due to space limitations we will focus on the first five priorities.

1. Improving maternal health. Rate of feto-neonatal and maternal deaths are indices that reflect the level of maternal health in Puerto Rico. The five (5) years needs assessment showed that half of all women began pregnancy with either a low BMI or at the obese level. This is a risk factor for pregnancy and perinatal complications affecting the mother as well as a risk factor affecting the unborn baby. Similarly, the WIC program reported that the most common reasons for a pregnant woman to be enrolled in the program were obesity or underweight, inadequate weight gain during pregnancy, or anemia.

Most fetal deaths are related to problems associated with maternal health prior to pregnancy, as well as complications arising during the course of the pregnancy and problems related to the quality of care during pregnancy and delivery (fetal asphyxia).

ESMIPR 2004 found a prevalence of 28.4% of pregnant women requiring one to four hospitalizations during her last pregnancy. The most common reasons for these hospitalizations were premature contractions, vomiting and dehydration, urinary tract infections, placental problems and hemorrhage, blood pressure (eclampsia), diabetes, and others. These data do not include a significant proportion of pregnant women with health conditions such as asthma who are adequately managed as outpatient cases.

To address this priority need it is imperative to assure availability and accessibility to pre-pregnancy services (i.e. family planning), early and regular prenatal care, perinatal care rendered at the most appropriate level of service according to the identified risk, postpartum and interconceptional care. These services are considered direct services according to the MCH pyramid.

The focal area 16 of HP 2010 provides several measures to help us monitoring this priority. These include: objectives 16-4 aimed at reducing maternal death; 16-6 (PM-18) aimed at increasing the proportion of women who receive adequate prenatal care; 16-9 to reduce cesarean section among low-risk women; and 16-17 to increase abstinence from alcohol, cigarette smoking and illicit drug use among pregnant women.

Enabling Services: Among the enabling services are the Home Visiting Program (PR State PM1), the toll-free line, postpartum education provided by perinatal nurses, the WIC program and others.

Population Based Services: At the community level a diversity of educational activities are conducted aimed at creating awareness on several health issues and promoting healthy behaviors among women during pregnancy and the interconceptional period. These educational activities are reinforced with distribution of written education materials. The importance of maintaining an appropriate weight, the need for an annual check up, the importance of early and regular prenatal and its content are emphasized.

Infrastructure Building Services: The PR Title V program's staff is actively engaged at this level of the pyramid in activities aimed at promoting a decrease in maternal complications and deaths. Among these are conducting needs assessments to understand better the prevalence and geographic distribution of health problems. The findings are used to raise awareness among concerned stakeholders; policy development; development and distribution of standard of care for the MCH population groups; quality assurance; implementation of a maternal deaths surveillance system; active participation in coalitions and committees concerned with the promotion of maternal health; professional development, and many other activities.

2. Reduce unintended pregnancies. The HP 2010 agenda (Focus Area 9) has set the target that by 2010, 70% of all pregnancies should be intended. However, in PR there is a wide gap between current proportion of intended pregnancies and the set goal. Findings from the ESMIPR 2004 revealed that almost 7:10 (66.8%) of surveyed recent mothers did not plan their most recent pregnancy. In addition, 12.7% said they did not want their most recent baby. Therefore, it is estimated that over 34,000 babies are born in PR who are not planned. In addition, nearly 6,500 are not wanted by their mother at the time of birth.

Unwanted pregnancies are associated with higher rates of abortion on demand, later or no prenatal care, unhealthy behaviors such as smoking, alcohol use, drug abuse and domestic violence. This situation leads to maternal complications and poor birth outcomes, including higher rates of LBW and prematurity, infant mortality, lower rates of breastfeeding and child neglect and abuse, among others.

It is important to mention that there is the knowledge and technology to prevent unwanted pregnancies. However, this requires personal commitment and responsibility at the time of expressing sexuality. On the other hand, comprehensive family planning services must be available and accessible at the community level for those persons who voluntarily want to control the number and spacing of children.

Direct Services: In Puerto Rico there are four entities that render family planning services. The Department of Health through the GIP provides male and female sterilizations. Contraceptive methods are complemented by means of Title V funds. Other entities are the Title X (Grantee is the School of Medicine), 19 federally funded 229/330 programs and PROFAMILIA, a non-for profit organization. This entity recently received approval of a Title X Grant.

Enabling Services: The toll-free line and the Home Visiting Program, which provides interconceptional services up to two years after the birth of the baby to all its participants and coordinates needed services at the community level.

Population Based Services: Community awareness through small group orientations, dissemination of educational materials. In addition, in collaboration with the Department of Education, the Title V program has implemented a peer group program and curriculum to promote abstinence education throughout the Island.

Infrastructure Building Services: The activities include needs assessment, dissemination of data, professional development and the promotion of public policy.

3. Improve newborn health. Focus Area 16 of HP 2010 establishes several objectives that help us to monitor the health of newborns. Among these are the percentage of LBW and VLBW babies, the perinatal, neonatal, postneonatal and infant mortality rates, etc. The target set for the IMR is no more than 4.5 infant deaths per 1,000 live births for all states, jurisdictions and ethnic groups. In 2003, the IMR in PR was 9.8/1,000 LBs. This rate is 2.1 times higher than the set target and 1.4 times above the U.S. mainland.

The determinant causes for the observed IMR are prematurity and the percentage of LBW/VLBW. Congenital anomalies are the second cause of IM in PR. Among the most frequent congenital anomalies are heart defects and NTDs. It is important to mention that a significant proportion of infants with congenital anomalies survive the neonatal and post neonatal periods to die later at the preschool and school age periods. As a matter of fact, congenital malformations are the third leading cause of death in children between 1-4 years of age in the Island.

LBW and VLBW lead not only to higher IMRs, but also to CSHCN. This group of children require a large amount of resources, programs and services from different public and private entities to address their complex needs.

Direct Services: The GIP provides preventive, primary and some specialized services. The Department of Health complements specialized services with Title V and state funds (Pediatric Centers and the Pediatric Pulmonary Center), the Department of Education and various non-governmental organizations support the needs of this population.

Enabling Services: Toll-free line, APNI (Asociacion de Padres de Ninos con Impedimentos), case management for children 0-3, Home Visiting services, and others.

Population Based Services: Among the group of services geared to improving the newborn health are the newborn screening program for congenital hereditary diseases, newborn hearing screening, immunizations, folic acid prevention campaign and Early Intervention Program (Law 51, 1996).

Infrastructure Building Services: Needs assessment, Registry of Congenital Anomalies, Autism

Surveillance, public policy. Law 51 of 1996 sets forth the development of standards of care, quality assurance, coalitions and committees concerned with the attention of the needs of the population with special health care needs.

4. Reduce adolescent pregnancy. The roots of the problem of adolescent pregnancy are multifactorial and very complex. Therefore, there are no simple strategies to address this public health problem. The need to involve a wide array of stakeholders is crucial in addressing adolescent pregnancy. These include, but are not limited to the family, adolescent themselves, the schools, Department of Health, CBOs, the media, private sector, and non-traditional partners such as the faith community.

Currently, in PR nearly 25 women under 20 years of age become mothers every 24 hours, some as young as 10-14 years of age. Nearly eight out of 10 are unwed and over 90% hold the GIP. Definitely this is a social problem that impacts women in the early reproductive period, their children, families and the society at large.

Direct Services: GIP with prenatal and maternity services, newborn and pediatric services, early intervention services, family planning services, among others.

Enabling Services: WIC program and Home Visiting services.

Population Based Services: Comprehensive Adolescent Health Services with peer groups, and abstinence education program.

Infrastructure Building Services: Needs assessment, sharing of data, coalitions, public policy, professional development, coordination of services, etc.

5. Reduce behavioral risk factors among pregnant women and adolescents. A significant proportion of pregnant women are engaged in unhealthy behaviors such as smoking, alcohol consumption, illegal drug use and abuse and unprotected sex. These behaviors are contributing factors for the high rates of LBW, premature labor and congenital anomalies which are the determinant factors for our higher rates of IM in the Island. Therefore, we need to address these behaviors in order to improve the maternal and newborn health.

Similarly, our adolescent population involves in behaviors such as smoking, alcohol and illegal drug use and unprotected sexual activity. These behaviors are the root of delinquency, violence (homicides) and motor vehicle crashes with its consequences: deaths and injuries.

#### C. NATIONAL PERFORMANCE MEASURES

Performance Measure 01: The percent of newborns who are screened and confirmed with condition(s) mandated by their State-sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) who receive appropriate follow up as defined by their State.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]					
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance	11 90	95.9	96	96.1	96.3

Objective					
Annual Indicator	96.1	95.8	94.7	95.4	95.8
Numerator	57156	53624	50081	48468	49079
Denominator	59460	55983	52871	50803	51223
Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual	96.5	96.7	96.9	97.1	97.5

#### Notes - 2002

Numerator provided by the Newborn Screnning Program.

Denominator from birth data files provided by Office for System Development.

## a. Last Year's Accomplishments

Law No. 84, enacted in 1987, mandates that every infant born alive in Puerto Rico must be screened for PKU, hypothyroidism and sickle cell anemia. The Neonatal Screening Program for Hereditary Diseases is located at the University Pediatric Hospital. This program is supported with \$200,000 earmarked by the Legislature.

Form 6 summarizes the newborn screening activity and its results during calendar year 2004. During calendar year 2004, it served 49,079 out of 51,223 live births. This figure represents 95.8% of all live born during the reporting year. Twenty-three (23) cases were diagnosed for the five conditions screened for in Puerto Rico: PKU-0 cases; hypothyroidism-10 cases; sickle cell anemia-11 cases, congenital adrenal hyperplasia- 2 cases and galactosemia-0 cases. All these patients received appropriate counseling, treatment, referrals to the endocrinologist, metabolic clinics and the WIC program as required. The WIC program provides special formulas if recommended by the specialist for those under five (5) year age. The Pediatric Centers provide formulas for children over 5 years.

Other activities supported by the staff of the MCH program include, but are not limited to, anticipatory guidance to all participants of the Home Visiting Program during the prenatal period and postpartum education by the perinatal nurses.

Postpartum Education: Title V funds are used to pay the salaries of 8 perinatal nurses stationed at area and regional hospitals. These nurses are key for the provision of postpartum education on an individual or group basis, making referrals to primary services, to home visiting nurses, disseminating educational materials and collecting information. During the reporting period the perinatal nurses conducted 14,183 individual orientations and 6,051 postpartum women were reached through group sessions. On the other hand, the Home Visiting Nurses served 10,703 pregnant women and children under 2 years of age. Orientation regarding the importance of newborn screening for congenital diseases is a standard topic provided by the Home Visiting nurse to all pregnant women admitted to the program. Also, 2,691 persons were reached at the community level with orientations concerning the importance of newborn screening for hereditary diseases.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities Pyramid Level of Service

	DHC	ES	PBS	IB
1. Screen all newborns for congenital hereditary conditions: T4, PKU, Sickle Cell, and Galactosemia.	Х			
2. Monitor compliance with the law at individual birthing institutions.				X
3. Link infants with genetic and metabolic disorders with nutritional and specialized medical care.		х		
4. Provide anticipatory guidance on newborn screening to all Home Visiting participants.	Х			
5. Provide genetic counseling to families of newborns with genetic or metabolic conditions.	Х			
6. Continue efforts directed at linking newborn screening data files with birth certificates.				X
7. Convene the new Council members of the Hereditary Diseases Screening Program as soon as they are nominated by the Governor.				X
8. Initiate a Pilot Project aimed at increasing the number of conditions to be screened.				X
9.				
10.				

### b. Current Activities

In section (a), it was mentioned that the Puerto Rico Newborn Screening for Hereditary Diseases program is mandated by law. The program is within the infrastructure of the Pediatric University Hospital. The MCH program is a partner in pursuing that all newborns be screened before hospital discharge.

It is important to highlight that the most important current activities concerning this performance measure are quite similar to those described earlier. These are the following:

- \* To screen all newborns for congenital hereditary diseases such as hypothyroidism, PKU, sickle cell anemia, galactosemia and congenital adrenal hyperplasia.
- \* To refer children with PKU and galactosemia to the WIC program for nutritional education and management.
- \* To refer children with genetic and metabolic disorders to the Pediatric Habilitative Centers for specialized follow-up as required.
- \* To provide prenatal counseling to all Home Visiting participants regarding the importance of the newborn screening.
- \* To provide postpartum education stressing the importance of asking the pediatric providers for the newborn screening results during the first pediatric visit.
- \* To disseminate appropriate educational materials.
- \* To follow-up the institutions with low newborn screening rates by written communication.
- \* To develop the mechanisms to link data from birth files with data from the Newborn Screening program.
- \* To continue our efforts in achieving 100% newborn screening in all birthing institutions.

## c. Plan for the Coming Year

Please refer to Figure 4a for the proposed activities for performance measure #1. Most activities proposed for FY 2005-2006 are quite similar to those described earlier in sections (1a) and (1b).

The most significant new activity for the coming year is the purchase of a Tandem Mass Spectrometry equipment. The cost of this equipment is close to \$400,000. In addition, the laboratory staff will be trained for the proper utilization of the new equipment in order to start a pilot project to increase the number of conditions to be screened for.

Performance Measure 02: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)

	Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004			
Annual Performance Objective					0			
Annual Indicator	NaN	NaN	NaN	NaN	44.8			
Numerator	0	0	0	0	162			
Denominator	0	0	0	0	362			
Is the Data Provisional or Final?				Final	Provisional			
	2005	2006	2007	2008	2009			
Annual Performance Objective	45	49	51	54	57			

#### Notes - 2002

Puerto Rico is not included in the National CSHCN Survey; consequently, family satisfaction data is not available at present. For next reporting year, we will obtain the denominator from the number of CSHCN 0-18 years old being served at the seven pediatric centers in Puerto Rico. The numerator is going to be obtained from a family survey.

### Notes - 2003

Puerto Rico is not included in the National CSHCN Survey; consequently, family satisfaction data is not available at present. A family survey will be done to collect data for this performance measure. The medical home family survey instrument will be revised to include questions to collect data for this indicator. The questionnaire will be validated and tested before the survey implementation. Activities are under way to select the sample among the Title V population served at the Pediatric Centers. Puerto Rico will initiate activities to revise, adapt and validate the SLAITS-CSHCN survey module questionnaire for the puertorrican population. Next step is to perform the study to collect data for NPMs 2, 3, 4, 5 and 6.

Puerto Rico is not included in the national SLAITS, CSHCN survey. As an alternative, the Division of Habilitation Services of the Department of Health performed a family survey (n=377) during the months of January and February 2005 with a sample of families with children with special health care needs that receive services at the Pediatric Centers (population=8,214). The survey questionnaire included two (2) scale questions selected from the SLAITS, CSHCN Survey to collect baseline data for this performance measure. The answers from the questions were recoded and then combined to obtain a proportion based on those families who answered both questions (valid cases n=362). This is the first intent made to obtain data for the CSHCN performance measures; the results are specific for the Pediatric Centers population and cannot be generalized to the population of CSHCN in Puerto Rico.

## a. Last Year's Accomplishments

The SLAITS-CSHCN Spanish questionnaire version was obtained and revised to select items to be included in a CSHCN survey with the Title V Pediatric Center's population. The medical home questionnaire for families was also revised, adapted and validated.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
Perform a survey with a sample of families of CSHCN at Pediatric Centers.				X	
Develop a plan with active family participation to achieve CSHCN PMs.				X	
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

#### b. Current Activities

A survey was performed with a sample of families with children with special health care needs that receive services in the pediatric centers in the Island. The questionnaire was administered during the months of January and February 2005. The medical home family survey instrument was revised and updated after revision of the SLAITS-CSHCN questionnaire to select and include questions with the purpose of collecting data for the national performance indicators related to this population. The instrument collects data related to health insurance coverage, utilization of services, measurement of child well being, medical home, need assessment of families and access to services their children need, among other useful information. A sample (n=377) was calculated using the active records in the information system as of December 2004 and then stratified by pediatric center. The survey questionnaire included two (2) scale questions selected from the SLAITS, CSHCN Survey to collect baseline data for performance measure #2. The results are based only on valid cases (n=362). Valid cases are those persons who answered both questions. Please refer to the note in Form 17 for more details.

Analyses of the responses revealed that 85% of families reported that doctors and providers who provided care to their children, always or usually made them feel like partners in caring for

them. Forty six percent (46%) of families said they were very satisfied with the services received. This question addressed the issue of services meeting the needs of families. From these results, around forty-five percent (45%) of the families of CSHCN reported that they participate in decision-making and are satisfied with the services they receive.

A meeting with Michael Kogan, PHD, Director of the Office of Data and Program Development, HRSA, MCHB, took place on February 2005 at the AMCHP annual conference to discuss our need to collect prevalence data and other information on CSHCN to enable us to properly address the Title V performance measures.

In year 2004, PR Department of Health was awarded a Champions for Progress Grant. This initiative provided an opportunity to join key partners with the purpose of advancing the medical home implementation throughout the Island. We firmly believe that medical home implementation in PR is medular to increase access to services for CSHCN and their families. Medical homes link newborn genetic and metabolic screening, hearing screening and the Birth Defects Surveillance System among others. The Champions for Progress Committee (CFP) composed of 18 representatives (including 6 families, 7 physicians and representatives from ASES and health insurance companies) has already identified the needs of families of CSHCN in accessing services as well as physician's barriers to establish medical home practices.

# c. Plan for the Coming Year

The findings from the study mentioned above are specific for the Pediatric Centers Title V population and cannot be generalized to the population of CSHCN in Puerto Rico. The data gathered provide baseline information for the Title V performance measures related to CSHCN. The information is also useful to plan activities for the coming year. Out next step is to request technical assistance for the purpose of adapting and administering the SLAITS-CSHCN Survey in Puerto Rico in order to obtain data from a representative sample of Puerto Rico.

The CFP initiative will extend until December 2005, upon completion of six (6) meetings, a final report will be submitted with recommendations to the health insurance companies, ASES and the Secretary of Health aimed to increasing the number of medical homes for CSHCN in Puerto Rico. Families who participated in the CFP initiative will be invited to join a working group composed of parents, providers, agencies and organizations with the purpose of developing a plan geared to accomplish the five CSHCN National Performance Measures.

MCH Title V technical assistance will be requested to develop, adapt, test and implement the Spanish version of the SLAITS-CSHCN survey to the general population in Puerto Rico.

Performance Measure 03: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)

Annual Objective and Performance Data  Annual Performance Objective  Annual Indicator  Annual Indicator  NaN NaN 38	Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Performance Objective	Objective and Performance	2000	2001	2002	2003	2004	
Annual Indicator NaN NaN 33	Performance					0	
	Annual Indicator			NaN	NaN	38.7	

Numerator			0	0	127
Denominator	0	0	0	0	328
Is the Data Provisional or Final?					Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	41	43	45	46	48

#### Notes - 2002

Puerto Rico is not included in the CSHCN Survey; consequently, the number of CSHCN who receive coordinated, ongoing, comprehensive care within a medical home is not available. Nevertheless, we have undertaken several initiatives in order to promote and develop the medical home concept in Puerto Rico: a brochure about medical home was designed and distributed through the Island; educational and training materials from the AAP were translated to Spanish and culturally adapted to our population; a Medical Home conference was held with the participation of more than 200 persons, including service providers, community agencies, pediatric centers staff and family representatives; a total of seven (7) regional training sessions were offered using the "train the trainer" approach with the participation of 556 persons, including family members; 16 families and 17 physicians became voluntary trainers and had an active participation in the regional training sessions.

The Puerto Rico Medical Home Project will continue working and will be offering training to service providers, community agencies representatives, and family members. One of the planned activities is the identification of physicians who could be mentors in each of the health regions in Puerto Rico and to continue the collaboration with the Puerto Rico AAP Chapter to promote the medical home approach among service providers.

A family survey instrument was constructed and will be implemented in FY 2003-2004. Activities are under way to determine the sample number to assure a representative sample of the population.

For next reporting year, we will obtain the denominator from the numbre of CSHCN 0-18 years old being served at the pediatric centers in Puerto Rico. The numerator is going to be obtain from a family survey.

The annual performance objective for year 2003 (5%) was estimated based on the short period (3 years) of public awareness of the Medical Home concept in Puerto Rico.

#### Notes - 2003

Puerto Rico is not included in the National CSHCN Survey; consequently, the number of CSHCN who receive coordinated, ongoing, comprehensive care within a medical home is not available at present. Nevertheless, we have undertaken several activities in order to promote and develop the medical home concept in Puerto Rico (see performance measure narrative).

A family survey will be done to collect data for this performance measure. The medical home family survey instrument will be revised to include questions to collect data for this indicator. The questionnaire will be validated and tested before the survey implementation. Activities are under way to select the sample among the Title V population served at the Pediatric Centers.

The annual performance objective for year 2003 (5%) was estimated based on the short period (3 years) of public awareness of the Medical Home concept in Puerto Rico.

Puerto Rico will initiate activities to revise, adapt and validate the SLAITS-CSHCN survey module questionnaire for the Puerto Rican population. Next step is to perform the study to collect data for NPMs 2, 3, 4, 5 and 6.

### Notes - 2004

Puerto Rico is not included in the national SLAITS, CSHCN survey. As an alternative, the Division of Habilitation Services of the Department of Health performed a family survey during the months of January and February 2005 with a sample (n=377) of families with children with special health care needs that receive services at the Pediatric Centers. The AAP survey questionnaire included forty-nine (49) scale questions distributed among the medical home components of accessibility, family centered services, comprehensive, continuous, coordinated, compassionate and culturally competent. The cases that answered usually or always were assigned a value of 1 in each of the questions. The numerator includes the number of cases that obtained a total value of 38 or more from the questions. The denominator is the number of families who answered 37 questions or more for this performance measure (n=328). This is the first survey performed to obtain data for the CSHCN performance measures, the findings from this study are specific for the Pediatric Centers' population and can not be generalized to the population of CSHCN in Puerto Rico. The findings can help us to develop activities to promote the medical home concept aimed at increasing the proportion of children who receive coordinated, ongoing, comprehensive care within a medical home in Puerto Rico.

## a. Last Year's Accomplishments

During the reporting period, strong collaboration has been established between the Puerto Rico State Early Childhood Comprehensive System (SECCS) Project, at present developing and sharing its vision, goals and objectives to address system partnerships for preschool children and families, and the Medical Home Project. The following agencies/organizations are actively collaborating in the SECCS Committee: Parent Training and Information Center; Title V; Early Head Start/ Head Start Programs, Healthy Start, Child Care Program, American Academy of Pediatrics (AAP), Health Services Administration; the School of Public Health of the University of Puerto Rico; Department of Education; Labor Department, United Fund, and Mental Health Service Administration. The School of Public Health and the AAP, active medical home collaborators, also joined the committee strengthening the SECCS Interagency Planning Committee by providing their expertise for the implementation of medical homes in Puerto Rico. We collaborated with the School of Public Health staff that is working in two academic Pediatric Clinics settings actually implementing the Medical Home concept.

In February 2004, the Division of Habilitation Services submitted a grant application to the Champions for Progress Center, Early Intervention Research Institute at Utah State University. The Champions for Progress Grant provides leadership for the development of service systems of care in support of children with special health care needs (CSHCN). Champions for Progress has three objectives: (1) to educate key stakeholders and families on the development of systems of care for CSHCN, including the six CSHCN (MCH) core outcome measures, (2) to develop collaborative strategies to establish partnerships between the families, health insurance companies and CSHCN Coordinators at the Pediatric Centers and (3) to develop a list for reimbursement codes identified by the teamwork.

The Champions for Progress Grant celebrated a multi-state meeting on May 24-26 in which we had the opportunity to share their experiences and constraints in building a system of care with national centers consultants such as Family Voices and the National Center for Cultural Competence, among many others.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Pyramid Level of

A ativities		Serv	vice	
Activities	DHC	ES	PBS	IB
1. Distribute a new brochure about the medical home concept to families receiving services at agencies.			X	
2. Include medical home information in the nursery discharge packets.			X	
<ol> <li>Distribute educational materials to families receiving services at agencies.</li> </ol>			X	
4. Continue identifying physicians or mentors at each health region to establish Medical Homes.				X
5. Train physicians in the use of CPT codes.				X
6. Meet with ASES and health insurance agencies to increase awareness of the medical home concept.				X
7. Train parents as interviewers to do the family interview of the survey.				X
8. Implement the survey to get data on the national performance measures for CSHCN.				Х
9.				
10.				

#### b. Current Activities

A survey was performed with a sample (n=377) of families with CSHCN that receive services in the Pediatric Centers in the Island. The questionnaire included questions from the translated, adapted and tested version of the AAP Medical Home Questionnaire in additional to some selected from the SLAITS. It included forty-nine (49) scale questions to collect baseline data for PM #2. The results are based only on valid cases (n=328).

The results shown that thirty-nine percent (39%) of families perceived that the services their children were receiving met the characteristics of a medical home. Families reported that sixty-five percent (65%) of the services they receive are culturally competent as well as comprehensive. They also reported that 63% of services are ongoing and family-centered. The service characteristics with the lowest positive response were; compassionate (61%), accessible (59%) and coordinated (59%).

The SECCS project incorporated as one of its five essential components, the Medical Home Subcommittee. They have been assessing the benefits (both economical as non-economical) of having medical practices transformed into medical homes, the need for more active participation at the state and the Legislature and the empowerment of these professionals with the knowledge of services available for children 0 to 5 years of age at the community, regional and/or state level. A questionnaire has been sent to pediatricians in order to assess the number of existing medical homes in the Island. During the period from December 2004 to March 2005, the Medical Home sub-committee developed a definition of medical home and a slogan for the medical home campaign. They also defined the screening instruments recommended for children 0 to 5 years of age, as well as identified the gaps in services.

Through "Champions for Progress", physicians will be encouraged to present to ASES the difficulties related with CPT coding they face when attempting to get reimbursement from the health care insurance companies. Hopefully, agreements among the parties will be finalized by December 2005. It is also expected that families will give their input as to the difficulties and their needs in accessing medical homes. An action plan to correct the gaps will be the result of these meetings to be completed by December 2005.

A System Development Conference was celebrated on March 11, 2005 with participation of

family representatives, medical insurance representatives and providers. Our special guest was Dr. Rodriguez Villar, representative of the AAP, who shared his experiences in serving CSHCN in medical homes in Arizona. An overview of system development principles was provided as well as real-life experiences in CSHCN pediatric family-centered practices. During the activity families and pediatricians expressed satisfaction for a unique opportunity to share their concerns and identify alternatives for solutions.

# c. Plan for the Coming Year

The Puerto Rico SECCS will continue working on the following activities, which at the same time will serve to empower families and physicians in the implementation of medical homes:

- \* Distribute a new brochure about the concept of medical home for both families and providers.
- \* Include medical home information in the nursery discharge packets.
- \* Continue distributing medical home educational materials to families wherever they receive services, including Departments of Health, Education, Family, etc.
- \* Continue identifying physicians or mentors at each health region and train them to establish Medical Homes.
- \* Promote incentives for the implementation of medical homes in collaboration with the health insurance companies, including training physicians in the use of CPT codes and appropriate documentation in medical records.
- \* Meet with ASES and the health insurance agencies to further advance awareness of the medical home concept through the "Champions for Progress" initiative.
- \* Train parents as interviewers to do the family interview of the survey.
- \* Distribute the educational material for providers describing the steps necessary to establish a medical home.
- \* Educate legislators so that they may promote the medical home concept among their peers.
- \* Finalize and have approval from the SECCS project officers of the Puerto Rico State Plan which will make medical homes accessible to families through licensed child care centers, Early Head Start/Head Start programs and community based organizations, among others.
- \* Make available a list of services in Puerto Rico for children 0 to 5 years of age through the web page of United Funds. Primary care physicians in their medical homes will learn to identify and recommend those services needed by their patients.
- \* Adopt health services indicators from the "National School Readiness Indicators Initiative" into the medical homes.
- \* Continue performing focus group activities at the community levels of each of the health regions in Puerto Rico to obtain information from the families regarding their health services' needs.

MCH Title V technical assistance will be requested to develop, adapt, test and implement the Spanish version of the SLAITS-CSHCN survey to the general population in Puerto Rico.

Performance Measure 04: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	

Annual Performance Objective					0
Annual Indicator			NaN	NaN	17.0
Numerator			0	0	53
Denominator	0	0	0	0	311
Is the Data Provisional or Final?				Provisional	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	18	19	20	21	22

### Notes - 2002

Puerto Rico is not included in the CSHCN Survey; consequently, the number of CSHCN with a source of insurance for primary and specialty care is not available.

The Pediatric Centers Information System (SI\_CEPED) has been updated to collect this data for the next reporting year. This system will provide specific data on an ongoing basis on the number of CHSCN with health insurance that pays for the services they need. Also, it will provide other useful information related to services provided to CSHCN upon referral.

For next reporting year, we will obtain the denominator from the number of CSHCN 0-18 years old being served at the seven pediatric centers in Puerto Rico. The numerator is going to be obtained from the information system (SI\_CEPED).

#### Notes - 2003

The Pediatric Centers Information System (SI\_CEPED) has been updated to collect data for this performance measure. The system provides specific data on an ongoing basis on the number of CHSCN with health insurance that pays for the services they need. Also, it provides other useful information related to services provided to CSHCN in the Pediatric Centers. However, since the definition for the numerator in the detailed sheet specifies that this number represents the number of families who perceive that they have adequate insurance coverage, we will include questions in the CSHCN family survey to collect data for this measure.

Puerto Rico will initiate activities to revise, adapt and validate the SLAITS-CSHCN survey module questionnaire for the puertorrican population. Next step is to perform the study to collect data for NPMs 2, 3, 4, 5 and 6.

#### Notes - 2004

Puerto Rico is not included in the national SLAITS, CSHCN survey. As an alternative, the Division of Habilitation Services of the Department of Health made a family survey (n=377) during the months of January and February 2005 with a sample of families with children with special health care needs that receive services at the Pediatric Centers. The survey questionnaire included five (5) questions selected from the SLAITS, CSHCN Survey to collect baseline data for this performance measure. The questions covered issues related to the adequacy of the health insurance including gaps in coverage, meeting of child's needs, reasonability of costs not covered and the insurance permitted the child to access the needed providers. The answers from the questions were recoded and then combined to obtain a proportion based on those families who answered the questions for this performance measure (valid cases n=311). However, we noted that questions included in the SLAITS-CSHCN survey are not specific and do not necessarily address the measure required. This is the first survey performed to obtain data for the CSHCN performance measures; the results obtained are

specific for the Pediatric Centers population and cannot be generalized to the population of CSHCN in Puerto Rico.

# a. Last Year's Accomplishments

The Pediatric Centers of the PRDOH continue to provide specialized services to children with special health care needs (CSHCN). The Pediatric Centers bill the health insurance companies and are reimbursed for services rendered under the Government Health Card (GHC) coverage. Also, the Division of Habilitation Services has been continuously involved in establishing and updating the Pediatric Centers' electronic database information system to obtain data for this NPM.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
Perform a survey with a sample of families of CSHCN at Pediatric Centers.				X	
Develop a plan with active family participation to achieve CSHCN PMs.				X	
3. Meet with ASES and health insurance companies to present CSHCN under insurance problems.				X	
4. Continue the medical home education to families and providers.			X		
5.					
6.					
7.					
8.					
9.					
10.					

#### b. Current Activities

A family survey was administered to a sample of families with children with special health care needs that receive services in the Pediatric Centers in the Island. A sample (n=377) was determined using the active records in the information system and then stratified by pediatric center. The questionnaire was administered during the months of January and February 2005. The survey questionnaire included five (5) questions selected from the SLAITS, CSHCN Survey to collect baseline data for performance measure #4. The results are based only on valid cases (n=311). Valid cases are those persons who answered the five questions. Those who answered less than five questions were excluded from the analysis. Please refer to the note in Form 17 for more details.

According to the survey, 97% of the families had a health insurance plan at time of the interview. Of these, 72% had the government health card and 26% had a private plan. Two percent (2%) had both plans. Seventy (70%) percent of families reported no gaps in coverage during the year prior to the interview On the other side, 30% of families reported not having health insurance sometime during the last year. This is worrisome because CSHCN use services more frequently and they are more expensive. Seventy two percent (72%) of families reported that services under their health insurance coverage usually or always satisfy their children's needs. Twenty four percent (24%) of families reported that sometimes they had a health insurance that covered the services to satisfy the needs of their children. Thirty three percent (33%) of families reported that the costs not covered by insurance were usually or

always reasonable and 82% reported that the insurance usually or always permitted the child to access the providers needed. Findings indicate that despite the presence of laws and mechanisms to ensure referrals are provided, barriers to access still exist. Based on the results of the family survey, we can conclude that seventeen percent (17%) of CSHCN that receive services at the Pediatric Centers have adequate health insurance to pay for the services they need. As part of the data analyses, we noted that the questions included in the SLAITS not necessarily address the measure required.

# c. Plan for the Coming Year

The Division of Habilitation Services has identified the development and implementation of the Spanish version of the SLAITS-CSHCN survey in Puerto Rico as a priority. These activities will probably be initiated during the next twelve months. In the event that the completion of the survey is not expected by February 2006, it would be interesting to distribute the survey among families under private commercial plans' coverage. Another activity may consist of identifying how many of the complaints filed at the Office of the Patients' Ombudsman, established in year 2002, are from families of CSHCN and the reason for the complaint. As of April 2005, the Ombudsman's office also serves the population with private health insurance. We also recommend a meeting with ASES and the health insurance companies to present the need of CSHCN being underinsured.

Performance Measure 05: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)

	Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004			
Annual Performance Objective					0			
Annual Indicator			NaN	NaN	68.0			
Numerator			0	0	246			
Denominator	0	0	0	0	362			
Is the Data Provisional or Final?				Final	Provisional			
	2005	2006	2007	2008	2009			
Annual Performance Objective	70	71	73	75	76			

### Notes - 2002

Puerto Rico is not included in the CSHCN Survey; consequently, percent of CSHCN age 0-18 whose families report the community based service system are organized so they can use them easily is not available.

Puerto Rico submitted a proposal for a statewide early childhood comprehensive system. If approved, this project will facilitate the integration of services and resources for families and will allow the development of a system of services for families and children, including CSHCN.

A family survey instrument was constructed and will be implemented in FY 2003-2004. Activities are under way to determine the sample number to assure a representative sample of the population.

#### Notes - 2003

Puerto Rico is not included in the National CSHCN Survey; consequently, the percent of CSHCN age 0-18 whose families report the community based service system is organized so they can use it easily is not available at present. A family survey will be done to collect data for this performance measure. The medical home family survey instrument will be revised to include questions to collect data for this indicator. The questionnaire will be validated and tested before the survey implementation. Activities are under way to select the sample among the Title V population served at the Pediatric Centers.

The ECCS grant was approved during year 2003. This project will facilitate the integration of services and resources for families and will allow the development of a system of services for families and children, including CSHCN.

Puerto Rico will initiate activities to revise, adapt and validate the SLAITS-CSHCN survey module questionnaire for the puertorrican population. Next step is to perform the study to collect data for NPMs 2, 3, 4, 5 and 6.

#### Notes - 2004

Puerto Rico is not included in the national SLAITS, CSHCN survey. As an alternative, the Division of Habilitation Services of the Department of Health performed a family survey (n=377) during the months of January and February 2005 with a sample of families with children with special health care needs that receive services at the pediatric centers. The survey questionnaire included one question selected from the SLAITS, CSHCN Survey to collect baseline data for this performance measure. The question addressed the issue if the services were organized for easy use. The numerator is the number of persons who answered usually or always to the question. The denominator is the number of persons who answered the question (valid cases n=362). We understand that the SLAITS-CSHCN questions are not aimed at measuring community based services systems. We recommend adding more questions to this section. This is the first survey performed to obtain data for the CSHCN performance measures; the results obtained are specific for the Pediatric Centers' population and cannot be generalized to the population of CSHCN in Puerto Rico.

# a. Last Year's Accomplishments

The SLAITS-CSHCN Spanish questionnaire version was obtained and revised to select items to be included in a CSHCN family survey in the Pediatric Centers. The medical home questionnaire for families also was revised.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities			Pyramid Level of Service			
			PBS	IB		
1. Perform a survey with a sample of families of CSHCN at Pediatric Centers.				X		
2. Develop a plan with active family participation to achieve CSHCN PMs.				X		

3. Develop a directory of community-based services for CSHCN.			X
4. Continue the medical home education to families and providers.		X	
5.			
6.			
7.			
8.			
9.			
10.			

### b. Current Activities

Services for CSHCN in PR are certainly fragmented; even though families of CSHCN strive to access services, a great majority (68%) reported in the survey that the services were usually or always organized for easy use and accessibility. We understand that this SLAITS question is not culturally adapted to our population. In order to measure if our services are community-based, another question needs to be formulated and the results compared.

The Champions for Progress Grant with its opening activity on May 2004, definitely offers our population, especially parents, the opportunity to work together with professionals to improve access to care for CSHCN and families in Puerto Rico.

As a result of the State Early Childhood Comprehensive System (SECCS) initiative, it is expected that agencies and organizations sharing common goals for the 0-5 population, including CSHCN, develop and implement a strategic plan for the effective development of community-based service systems in Puerto Rico. In recent years, the Early Head Start/Head Start Programs and the State Systems Development Initiative (SSDI) regional working groups have also provided a forum for regional and local discussions on critical issues for this population. Concerns have been forwarded to the appropiate agencies.

# c. Plan for the Coming Year

The Division of Habilitation Services along with the Champions for Progress group will constitute a Committee to develop a plan with ongoing activities to achieve National Performance Measures 2-6. A directory of community based services for children 0 to 5 years will be implemented through SECCS by year 2007. The Pediatric Centers in Puerto Rico will expand this directory to include the services for the population up to 18 years of age. Activities to accomplish this will be ongoing from 2005 to 2007.

Performance Measure 06: The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]					
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective					0
Annual Indicator			NaN	NaN	9.1

Numerator			0	0	9
Denominator	0	0	0	0	99
Is the Data Provisional or Final?				Provisional	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	10	12	14	16	18

#### Notes - 2002

Puerto Rico is not included in the CSHCN Survey; consequently, the percentage of youth with SHCN who received the services necessary to make transition to all aspects of adult life is unknown.

To obtain this information, the CSHCN Program will develop collaborative agreements with the Department of Education and the Vocational Rehabilitation Program to share data and strategies to facilitate the integration of youth with SHCN to all aspects of adult life. A collaborative group will be identified during the current year, including DOE, Vocational Rehabilitation Program, parents and youth, Council on Developmental Disabilities and Center for Excellence in Developmental Deficiencies to perform a need assessment of this population, develop a baseline data, and develop a work plan to improve outcomes for this population.

A family survey instrument was constructed and will be implemented in FY 2003-2004. Activities are under way to determine the sample number to assure a representative sample of the population.

#### Notes - 2003

Puerto Rico is not included in the National CSHCN Survey; consequently, the percentage of youth with SHCN who received the services necessary to make transition to all aspects of adult life is unknown.

To obtain this information, the CSHCN Program will develop collaborative agreements with the Department of Education and the Vocational Rehabilitation Program to share data and strategies to facilitate the integration of youth with SHCN to all aspects of adult life. A collaborative group will be identified during the current year, including Department of Education, Vocational Rehabilitation Program, parents and youth, Council on Developmental Disabilities and the University Affilliated Program Center of Excelence to perform a need assessment of this population, develop baseline data, and develop a work plan to improve outcomes for this population.

Puerto Rico will initiate activities to revise, adapt and validate the SLAITS-CSHCN survey module questionnaire for the puertorrican population. Next step is to perform the study to collect data for NPMs 2, 3, 4, 5 and 6.

Also, a family survey will be done to collect data for this performance measure. The medical home family survey instrument will be revised to include questions to collect data for this indicator. The questionnaire will be validated and tested before the survey implementation. Activities are under way to select the sample among the Title V population served at the Pediatric Centers.

#### Notes - 2004

Puerto Rico is not included in the national SLAITS, CSHCN survey. As an alternative, the Division of Habilitation Services of the Department of Health made a family survey (n=377) during the months of January and February 2005 with a sample of families with children with

special health care needs that receive services at the pediatric centers. The survey questionnaire included four questions selected from the SLAITS, CSHCN Survey to collect baseline data for this performance measure. Some questions were related to the role of physicians in talking to families about the changing needs during adulthood and the shift to an adult provider, if a plan was elaborated to address the changing needs and if the child has received vocational or career training in preparation to adult life. The numerator for the PM is the number of persons who answered affirmatively to the four questions. The denominator is the number of persons who answered the four questions (valid cases n=99). This is the first survey performed to obtain data for the CSHCN performance measures; the findings from this study are specific for the pediatric centers population and cannot be generalized to the population of CSHCN in Puerto Rico.

# a. Last Year's Accomplishments

Puerto Rico has received informal reports that lead us to suspect that transition from school to adult life is a critical issue, as it is for many states in US. However, we don't have data on the percentage of adolescents with CSHCN who receive the services necessary to make transition to all aspects of adult life.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Identify agency representatives that can be part of a collaboration task force.				X	
2. Identify families for participation in a task force for data collection and analysis.				X	
3. Development of a working plan by the task force.				X	
4.					
5.					
6.					
7.					
8.					
9.					
10.					

#### b. Current Activities

The family survey administered to families revealed that doctors of fifty-seven percent (57%) of families did not talked about changing needs, as child became adults. Sixty-six percent (66%) of children did not have a plan for addressing the changing needs. In only 34% of families, their doctors discussed the shift to an adult provider. Only 14% of adolescents have received vocational or career training in preparation for adulthood. In general, only 9% of youngters with special health care needs have received guidance and support in the transition to adulthood.

In March 2005, the Centers for Excellence Institute on Developmental Disabilities of the School of Public Health, invited the DHS to participate to the first meeting of the Alliance for Full Participation whose mission is to impact the lives of persons with developmental disabilities to increase their opportunities to develop self-determination, independence, productivity and inclusion at the community level. Representatives from the Legislature, families, community organizations, consumers with developmental disabilities and other conditions as well, including agencies were present. Members were divided into subgroups to jointly assess this population's needs. In the discussions, the needs of youth with special health care needs facing

the transition to adult life were identified as a priority. This information will be included in a report, which will be presented in a summit to be held in September 2005 at Washington, DC: Many Voices, A Mission to a group of legislators. We will adopt the mission that results from this summit.

# c. Plan for the Coming Year

A task force will be identified during the current year, including the Department of Education, the MCH Adolescent Program (SISA), Vocational Rehabilitation Program, parents and youth with CSHCN, Council on Developmental Disabilities, and the University Affiliated Program Center of Excellence to perform a needs assessment of this population, develop/collect baseline data and develop an agenda and a work plan to improve outcomes for this population.

MCH Title V technical assistance will be requested to develop, adapt, test and implement the Spanish version of the SLAITS-CSHCN survey to the general population in Puerto Rico.

Performance Measure 07: Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	90	92	92	92	92	
Annual Indicator	94.1	93.4	NaN	56.9	92.7	
Numerator	942	4226	0	566	921	
Denominator	1001	4524	0	994	994	
Is the Data Provisional or Final?				Final	Final	
	2005	2006	2007	2008	2009	
Annual Performance Objective	93	93.5	94	94.5	95	

## Notes - 2002

Data for 2003 is not available. The Immunization Program will probably complete the coverage survey by December 2003.

# a. Last Year's Accomplishments

Law 25 of 1983, mandates immunization of children according to the latest immunization schedule approved by the Secretary of Health of Puerto Rico. Recently the Immunization Program of the Puerto Rico Department of Health has begun conducting bi-annual immunization coverage studies to monitor compliance with established national and local guidelines. For the purpose of the study a full schedule of immunization for children 35 months

of age consists of 4 (DTaP), 3 (IPV/OPV), 3 (HiB), 1 (MMR) and 3 Hepatitis B vaccines. The study entails conducting house to house interviews with a random sample of parents of children 35 months of age and documenting their immunization status.

The latest immunization study revealed local catch up activities have been able to return vaccination coverage to 2001 levels and that delayed immunization associated with the DtaP vaccine shortage has been surmounted. After reaching their lowest levels in March 2002, when the rates fell down to 32%, rates have begun to steadily increase. Levels rose to 57 percent in January 2004 and by August 2004 they had reached 79%. The most recent study conducted in February 2005 revealed 93% of 35 month olds had received a full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, Hepatitis B. However, if only 3 DTaP doses are considered, the level rises to 95%. Coverage for single antigens was even higher. Ninety eight (98%) had evidence of 3 doses of the Polio and 98% of children had 1 MMR dose. A complete series of Hepatitis B vaccines and HIB was documented in 97% of the children included in the study. In addition to determining coverage for 35 month old children, the Immunization Program of the Puerto Rico Department of Health determines the percentage of 24 month old children who had 4 doses of (DTaP), 3 (IPV/OPV), 3 (HiB), 1 (MMR) and 3 Hepatitis B vaccines. The rate for 24 month old children included in the February coverage study was 77.4%.

This level of coverage is a reflection of the multiple collaborative efforts the Puerto Rico Department of Health has been able to establish with public and private entities such as WIC, Private Insurance Companies, providers, schools, pharmacies, food chain stores, pharmaceutical companies among others. A key collaborator has been the Maternal and Child Health Division. Our Home Visiting Nurses and outreach workers are constantly reminding participants and the community at large of the importance of adequately immunizing their children during home visits, school activities and health fairs. During 03-04, children from the 6,373 families in the HVP were evaluated for the adequacy of their immunization status; counseled and referred for vaccination if needed. In addition 4,935 individuals participating in 546 group meetings received information on the importance of children's immunizations.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Assess and promote adequate immunization for children participating in the Home Visiting Program.		X			
2. Collaborate with the immunization program initiatives to promote disease prevention.			X		
3. Identify and address system barriers which affect access to immunizations.				X	
4. Monitor immunization rates by municipalities and health regions.				X	
5. Update the immunization knowledge of the MCH staff (Home Visiting Nurses and Outreach Workers).				X	
6. Use diverse community level interventions to disseminate the current immunization schedule.			X		
7.					
8.					
9.					



#### b. Current Activities

Currently DTaP shortage has been resolved. Vaccine catch up activities such as special clinics and extended clinic hours continue to take place throughout the island. All these factors have contributed to the increased vaccination coverage present in the Island children. This year we were able to surpass our goal of 92% by 1%.

During this year an aggressive campaign was conducted to encourage high risk children (following CDC recommendations) and pregnant women get vaccinated with the Influenza Vaccine. So far over 10,000 children 6-23 months of age have received this vaccine this season. Currently, the strategy used this year is under review and additional strategies are being considered for next season in order to reach a larger number of children when the new vaccine becomes available next autumn.

The system has faced several challenges this year. The most significant one was the shortage of the Prevnar vaccine due to reduced availability. As a direct consequence the Puerto Rico Department of Health had to reduce the number of doses of the vaccine required for school entrance to three. This situation is being monitored constantly and now that the vaccine is available the requirements will again be increased to previous levels. Vaccination of underinsured children continue to be a challenge. Additional local funds have been requested in order to increase the availability of vaccines for these children. Other barriers that have been identified are missed opportunities and some mothers and fathers concerns with development of autism in their children due to vaccines.

In order to respond to these challenges Home Visiting Nurses and Outreach Workers continue to educate and promote compliance with the established vaccine schedule during their home visits, school activities and health fairs. In those cases where they identify a particular need in the community, a clinic is organized in conjunction with the Immunization Program to administer them. In addition the PRDH webpage has a link to the Immunization Program monthly publication called INFOVAC. In it they provide up to date information on all current issues regarding immunization such as the vaccine shortage, adverse effects, new recommendation and guidelines for school entrance requirements.

Currently providers from all eight (8) health care regions are participating in a continued medical education activity which include topics such as: vaccine costs and funding sources, adequate storage and transportation, vaccine reporting and the electronic reporting system, local laws and regulations regarding vaccine storage and administration, and an update on new vaccines being developed and recommendations for their use, epidemiology of vaccine preventable disease, adverse reactions and contraindications.

# c. Plan for the Coming Year

Currently one of the main motivators to adequately immunize children is the requirement of presenting the immunization record of children when they are enrolled in school every year. Our staff strives to increase awareness among those parents with whom they interact of the benefit of protecting them against diseases themselves and of not delaying immunizations until children are ready to enter school.

The core program of the Puerto Rico Title V program is the Home Visiting Program. Its target population is pregnant women and children up to 2 years of age with complex health and social problems. During their daily activities Home Visiting Nurses evaluate participants for the adequacy of their immunization status; counsel and refer for vaccination those in need.

Recently the MCH Division Outreach Program was strengthened. The existing manual was revised and services to be rendered redefined. Protocols for community interventions such as school activities, health fairs, prenatal and parenting classes include monitoring for compliance with the PRDH Vaccine Schedule particularly among children less than two years of age. In those cases where a significant need is identified in a community, Outreach Workers are expected to coordinate special immunization clinics with the Immunization Program in order to remedy the situation. As they integrate themselves in the community they will be better able to detect those barriers parents face when they attempt to vaccinate their children. Once identified they will collaborate with the immunization program and other community resources to eliminate them.

The information gathered during the home visits, outreach activities and during those activities conducted by the regional immunization program will help us monitor immunization rates by municipalities and health regions more effectively.

In view of the frequent changes and emergence of new modalities in the field of childhood immunizations it is necessary to constantly update the knowledge of the MCH staff (Home Visiting Nurses and Outreach Workers) and providers in general have regarding immunizations. To accomplish this we will continue to promote MCH Division staff and other health care providers receive regular updates during their monthly meeting regarding new development in the field by Immunization Program Regional Supervisors.

Finally we will collaborate with the Immunization Program Initiatives to increase the number of high risk children and pregnant women in their second and third trimester of pregnancy who receive the influenza vaccine during the Influenza season. We will continue to monitor and encourage women of childbearing age to have their rubella titers examined and if necessary receive a dose of the MMR vaccine during the postpartum period.

Performance Measure 08: The rate of birth (per 1,000) for teenagers aged 15 through 17 years.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	54	51.5	42.2	40.7	39.2	
Annual Indicator	47.2	45.5	42.2	40.7	41.1	
Numerator	4491	4150	3853	3624	3656	
Denominator	95055	91196	91196	89035	89014	
Is the Data Provisional or Final?				Final	Provisional	
	2005	2006	2007	2008	2009	
Annual Performance		36.2	34.7	33.2	31.7	

_				_	
Objective					
Notes - 2002					
Numerator is from birth file data provided by Office for System Development. Denominator is an estimate provided by the Puerto Rico Planning Board.					
a. Last Year's Accomplishments					

The 15 to 17 years old birth rate (per 1,000) in Puerto Rico continued its decrease from its peak in 1997 (59.9 per 1,000) to 40.7 per 1,000 in 2003 (a decrease of 32%).

The MCH Staff carried out 1,595 small group orientations reaching 30,130 participants across the Island. Topics included: sex education and teen pregnancy prevention. Abstinence topic was given to 717 people in 213 small groups.

The Abstinence Education Project (PRAEP) reached 31,966 public school students through the "Sex Can Wait Curriculum" and extracurricular and peer group activities in 299 public schools in 56 municipalities islandwide. Other activities performed reached 22,436 participants through parent workshops, summer camps, conferences and other educational activities.

The plan to reduce health disparities in prenatal care, to support continued studies and prevent repeated teen births of the "Healthy Beginnings" Project and PRAEP continued in ten municipalities. One regional activity and 27 local meetings gathered 428 professionals in 14 municipalities to raise awareness of teen pregnancy issues and to identify needs to be addressed by the Project.

The Comprehensive Adolescent Health Program (SISA Program) included positive youth development in teen pregnancy prevention efforts through the Peer Teen Health Promoters' Program. A total of 522 students of 32 middle public schools served as Teen Health Promoters around the island. They carried out 228 activities reaching about 12,745 students. The Secretary of Health issued the Proclamation of March: Teen Pregnancy Prevention Month in Puerto Rico. During that month the SISA Youth Health Promoters held twenty-eight (28) teen pregnancy prevention activities reaching 1,646 adolescents islandwide.

The SISA Program sponsored a Positive Youth Development Training on April 29-30, 2004 in collaboration with the Konopka Institute. Representatives (33 persons) from the public and private sector -including youth- attended the training. On June 5, 2004, training participants met to organize a Steering Committee, an action oriented group that collaborates with SISA in developing a culturally appropriated curriculum on Positive Youth Development and a train-the-trainer handbook to be disseminated islandwide.

The partnership with the community-based organization COPI in Pinones led to the creation of "Jovenes Creando Conciencia" a group of 15 youth health promoters. They developed a social theater play about teen pregnancy, drugs and alcohol use that was presented to the community. The anthropological research about teen pregnancy continued with a focus group interview and individual in-depth interviews.

SISA efforts continued to promote the establishment of the public policy to reduce teen pregnancies. Collaboration in the "Coalicion Pro Salud Sexual Reproductiva del Adolescente" continued.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service			
	DHC ES	PBS	IB	

1. Coordinate educational activities in schools and communities to prevent teen pregnancies.		x	
2. Distribute culturally appropriate educational materials directed at preventing teen pregnancies.		X	
3. Provide the Sex Can Wait Curriculum of the Abstinence Education Only Program to at least 50,000 students during FY 2005-2006.		Х	
4. Provide sex education and effective communication workshops to parents of school age children.		Х	
5. Continue the support to the SISA Program's Youth Health Promoters in middle public schools in collaboration with the Department of Education.			x
6. Provide teens with information on the importance of family planning services and how to access them.	X		
7. Continue the organization of the Positive Youth Development Initiative for Puerto Rico.			X
8. Promote the adoption of a public policy directed at reducing the rate of teen pregnancies.			X
9. Increase awareness on issues related with teen pregnancies among the general public.		X	
10.			

### b. Current Activities

The MCH Staff has continued its teen pregnancy prevention educational activities in schools and communities islandwide.

The Abstinence Education Program (PRAEP) offered the "Sex Can Wait Curriculum" and peer group activities in public schools. Extracurricular and educational activities were offered. The Middle School Curriculum' Spanish translation was finished. Four summer camps for 12-17 year old youths are in progress. A youth art contest was done for a school calendar and youths are participating in the production of videos on sexual abstinence. Parental workshops have continued.

The "Healthy Beginnings" project to reduce repeated teen births and school dropouts continued until December 2004. A total of 73 MCH facilitators received the "Comenzando Bien" training to offer pregnant teens. Meanwhile, the Comprehensive Adolescent Health SISA Program is developing a special curriculum for pregnant teens "Crianza con Amor" that stresses on preventing repeated teen pregnancies and promoting healthy parenting.

The Department of Health's theme for March: Teen Pregnancy Prevention Month in PR was "Connectedness is Protection". The SISA Program is developing workshops to involve parents and adults to connect to their children or youths. A pilot of Plain Talk/Hablando Claro will start in a PR community located in Naranjito. The SISA Program started the first High School Youth Health Promoter Group in Camuy. Currently, the SISA Middle School Program has 582 youth health promoters in 40 schools providing information and teen pregnancy prevention activities to their peers. The SISA Program continues creating awareness of the risk factors for teen pregnancy among students, health professionals and the public at large. A Youth Health Promoter's Initiative is in process in two juvenile justice institutions. The new Governor will consider the submitted Public Policy to Decrease Teen Pregnancies and the Plan of Action for Puerto Rico. The collaboration with "Red Pro Salud Sexual del Adolescente", an interagency and community network for teen pregnancy issues in PR continued.

The "Jovenes Creando Conciencia" Teen Health Promoters of the Pinones community: 1) developed and administered a questionnaire targeted at community youth issues; 2)

participated in a hygiene training sponsored by SISA; 3) offered workshops on teen pregnancy prevention to local 5th and 6th graders (57 students); 4) participated in a communities' youth leadership training and; 5) developed a youth dance troupe. They will offer the personal hygiene workshop to girls aged 10-14 on June.

"Reto y Esperanza": Healthy Puerto Rican Youth Development, an initiative in collaboration with Rochester University, NY ACT for Youth and the Konopka Institute was established and the Steering Committee is working to develop the positive youth development curriculum and train the trainer manual for Puerto Rico.

## c. Plan for the Coming Year

The MCH Staff will continue to provide adolescent pregnancy prevention educational activities and materials in schools, community programs or other entities.

The Abstinence Only Education Program (PRAEP) in conjunction with the Department of Education will continue to provide the Sex Can Wait Curriculum in its Spanish translation. Training regular teachers will prepare them to offer the curriculum. Peer group (AMORES) meetings in public schools will continue. These initiatives will also be implemented in private schools and among special health care need teens. Workshops for parents of school-aged children on communication about sexuality issues with their children will continue. A social theater company will offer public school's personnel a play about teen pregnancy issues and their role in preventing pregnant teen school drop outs including secondary abstinence to reduce repeated teen pregnancies. A TV media campaign will be started to promote teen sexual abstinence.

The Comprehensive Adolescent Health (SISA) Program will continue the training of youth health promoters in middle and high schools islandwide so they can continue spreading the message of teen pregnancy prevention to their peers through a variety of school based activities. A questionnaire to gather data on socio-demographic characteristics, health, skills and interests will be administered to the Peer Teen Health Promoters. The SISA Program will continue to work in developing awareness of teen pregnancy prevention giving special attention to educate parents and adults to connect to their sons, daughters and youths as a protection for conducts of risk. The Plain Talk/Hablando Claro pilot Project will start in the Sabana Community in Naranjito. The work to develop the "Crianza con Amor" Curriculum for pregnant teens will continue. Collaboration with the "Red Pro Salud Sexual Reproductiva del Adolescente" and the "Red AMAME" for pregnant teens will continue. The development of the Directory of Teen Health Services in Puerto Rico will continue in collaboration with government agencies and community based organizations. The collaboration with the Juvenile Justice Agency in PR will continue to develop the Youth Health Promoters. A pilot group will start in the female youth institution in Ponce.

The assistance to "Jovenes Creando Conciencia" Teen Health Promoters in Pinones will continue. The ethnographic study on teen pregnancy will be completed and a report will be submitted. An MCH Community worker will be offering services to the Pinones community on maternal-child and adolescent health.

The work of the Steering Committee of "Reto y Esperanza" Project will develop a positive youth development curriculum that will be tested in several sites. The Committee will also produce the train the trainer handbook. An evaluation plan will be implemented.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	13.7	14	14	15	20	
Annual Indicator	8.3	8.3	5.2	4.6	5.9	
Numerator	5246	5246	6391	5087	7067	
Denominator	63575	63575	122075	110950	119976	
Is the Data Provisional or Final?				Final	Provisional	
	2005	2006	2007	2008	2009	
Annual Performance Objective	10	12	14	16	18	

#### Notes - 2002

No data available for 2000 and 2001, we estimate no change on this figure.

We cannot obtain information for third grade. Instead we obtained information for those children age 8-9 who receive protective sealants on at least one permanent molar tooth from the Health Insurance Commissioner for 2002. Denominator are estimates obtained from Planning Board for 2001.

#### Notes - 2003

Data regarding the grade in which children are enrolled is not available in the billing forms. Information provided by the Health Insurance Commissioner reflected the number of 8 to 9 year old children who received protective sealants on at least one permanent molar tooth during the last year (2003). We recommend that this performance measure be revised to include age instead of grade in school.

#### Notes - 2004

Data regarding the grade in which children are enrolled is not available in the billing forms. Information provided by the Health Insurance Commissioner reflected the number of 8 to 9 year old children who received protective sealants on at least one permanent molar tooth during the last year (2004). We recommend that this performance measure be revised to include age instead of grade in school.

# a. Last Year's Accomplishments

As a result of the implementation of the Health Care Reform in Puerto Rico, all individuals under 200% of the poverty level hold a government-paid health plan. The government-paid health plan has an expanded coverage of direct health services which includes sealants for permanent molar teeth. Holders of the government insurance plan may access the dentist without a referral from their primary providers. A significant proportion of children hold private health insurance, which includes in its coverage the sealants for permanent molars.

Based on data provided by the Office of Health Insurance Commissioner and the Administration of Health Services (ASES, Spanish Acronym), over 98% of children and

adolescents had a health insurance plan in PR in 2004. However, only 7,067 children benefited from this preventive service in 2004. This figure includes both private and government insured children.

In 2003-2004, the Division of Oral Health Services carried out multiple orientations at elementary level public schools reaching 172,348 students between the first and six grades. Among the topics the personnel of the Oral Health Division includes the importance of protective sealants to prevent carries. The group orientations are supported with a flyer entitled "Consejos para una Sonrisa Saludable" ("Tips for a Healthy Smile"). The flyer includes a summary of the oral health services within the GIP package.

In addition, Home Visiting Nurses and Title V outreach workers promote the importance of the proper utilization of oral health services available through the GIP.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	Pyramid Level of Service				
	DHC	ES	PBS	IB		
Raise awareness among elementary school children about the importance of protective sealants. (PBS)			X			
2. Disseminate educational materials concerning the importance of protective sealants.			X			
Improve data collection mechanism to monitor this performance measure.				X		
4.						
5.						
6.						
7.						
8.						
9.						
10.						

#### b. Current Activities

During the current year the Division of Oral Health continues with the plan to promote the importance of dental sealants. Additionally, both MCH staff and the Director of the Division of Oral Health participated as collaborators and presenters in an Oral Health Forum organized by the Head Start Program. The forum took place in San Juan with the participation of about 80 attendees.

# c. Plan for the Coming Year

During the coming year the MCH program will continue the collaboration with the Division of Oral Health Services staff in the implementation of a plan to create awareness among parents about the importance of this preventive service. The other area that will be addressed is the development of a data collection mechanism to monitor this performance measure. To date, we continue confronting great difficulties in gathering the appropriate data, because the performance measure refers to third grade students. However, this information is not collected

through claims. Again, we recommend to the MCHB to change "third grade" to "children aged 8-9".

Performance Measure 10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

Tracking Performa [Secs 485 (2)(2)(B)(iii					
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	3	3	2.4	2.3	2.2
Annual Indicator	3.0	2.9	2.4	1.9	2.0
Numerator	27	26	22	17	17
Denominator	906308	901637	901637	882134	865067
Is the Data Provisional or Final?				Final	Final
	2005	2006	2007	2008	2009
Annual Performance Objective	1.9	1.8	1.7	1.6	1.5

### Notes - 2002

Numerator is from death file data provided by Office for System Development. Denominator is an estimate provided by the Puerto Rico Planning Board.

# a. Last Year's Accomplishments

Reducing unintentional injuries among infants, children and adolescents is one of the 10 priorities of the PR MCH program. In PR several public and private entities work in collaboration through the Safe Kids Coalition to promote the achievement of this performance measure. These include the Police Department, Traffic Safety Commission of the Department of Transportation, Fire Department, PR Coalition for the Prevention of Alcohol Use among Adolescents, Department of Education, EMSC and MCH programs and many other private entities.

MVCs are one of the most common causes of injury among children under 14 years of age. This issue must be addressed from may fronts and with the collaboration of many partners besides the MCH program.

One of the principal activities carried out on an ongoing basis is the analysis of Vital Statistics reports of deaths resulting from unintentional injuries. These deaths are analyzed by age groups and sex. The findings are used to raise awareness about the problem among providers and the public at large. The report is shared with the Safe Kids Coalition and the EMSC program. These entities use the information for press conferences, raising awareness, presentation to health professionals, and in training.

In addition, MCH program staff use the data and information to provide group orientation at the community level, and for the anticipatory guidance provided to all participant families of the Home Visiting program according to the stage of development of their children. A topic emphasized by the HVNs is the use of the infant seat restraint. Also, the perinatal nurses provide orientation about the importance of the infant seat to postpartum women.

During the reporting period, MCH personnel across the Island conducted several activities aimed at decreasing deaths due to MVCs. Among the topics presented at the community level were the importance of the infant seat restraint, the importance of seatbelt used among older children, prevention of unintentional injuries in general and security rules when crossing the streets. A total of 1,562 educational activities reaching 14,403 participants were documented.

Another activity used to raise awareness and educate the public at large is the dissemination of educational materials.

On the other hand, our collaborators, the Safe Kids Coalition, carried out 17 Car Seat Check Point events reaching 1,600 cars across the Island; 100 promotional banners with the message of car seat safety were posted at different bus stop shelters; and over 800 children in summer camps were educated concerning the importance of buckle-up and other safety messages. The coalition commemorated Unintentional Injury Prevention Week with a press conference.

The EMSC Program concentrated in raising awareness about the problem of unintentional injuries through 9 radio and TV programs, and enhancing the skills of health professionals through conferences, a symposium and 9 one week trainings for first responders.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	mid Serv	Leve vice	l of
	DHC	ES	PBS	IB
1. Promote adequate use of child restraints as part of anticipatory guidance at the community level.			X	
2. Inform families with limited resources about local programs renting infant car seats.		X		
3. Continue collaborating with the PR Safe Kids Coalition action plan.				X
4. Train Perinatal Nurses in installation and inspection of car seats.				X
5. Disseminate educational materials at the community level.			X	
6. Disseminate the report on the analysis of deaths caused by unintentional injuries among children and adolescents registered in 2003.				X
7.				
8.				
9.				
10.				

### b. Current Activities

During the current year, most of the activities described above are being conducted on an ongoing basis.

In May the MCH Director represented the Department of Health in a Press Conference conducted by the Traffic Safety Commission to promote the use of seat belts.

On June 13-18, 2005, Injury Prevention Week was celebrated. A press conference was carried out at the Offices of the Superintendent of the Police.

The MCH Division prepared a report describing all unintentional injuries occurring in Puerto Rico by age group and gender during 2003.

# c. Plan for the Coming Year

Figure 4a lists some of the activities that will be conducted in collaboration with our partners aimed at reducing deaths due to MVCs in children under 14 years of age.

Performance Measure 11: Percentage of mothers who breastfeed their infants at hospital discharge.

Tracking Performa [Secs 485 (2)(2)(B)(iii					
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	56	58	60	62	64
Annual Indicator	42.2	47.8	53.3	61.2	64.5
Numerator	941	1018	1113	389	622
Denominator	2230	2129	2088	636	965
Is the Data Provisional or Final?				Final	Final
	2005	2006	2007	2008	2009
Annual Performance Objective	66	68	70	72	74

#### Notes - 2002

This figure is obtained from ESMIPR, the PRAMS-like survey in Puerto Rico.

#### Notes - 2003

The data for this PM is obtained from a biennial customized PRAMS-like survey (ESMIPR). This survey is administered to recent mothers in postpartum wards. This year (2004) the questionnaire had to be submitted for review and approval to the IRB and HIPAA Committees of the School of Medicine. Unfortunately, it took four months to obtain the final authorization of both committees. Currently we are in the process of collecting the data from a representative sample of 1000 cases in 28 birthing hospitals. Preliminary data is provided.

#### Notes - 2004

The data for this PM is obtained from a biennial customized PRAMS-like survey (ESMIPR). This survey is administered to recent mothers in postpartum wards.

# a. Last Year's Accomplishments

A public policy to promote breastfeeding was established in 1995 by the Secretary of Health. An administrative order followed in 1998 requiring at least 3 CME credits on the topic for recertification of health providers. A Steering Committee including partner entities in breastfeeding promotion devised a 5-year plan to achieve the year 2000 objectives related to breastfeeding. All efforts have continued to reach the HP 2010 objectives regarding this issue.

During this reporting period, Title V staff carried out various breastfeeding promotion activities in PR, including:

- \*The MCH Program in the Mayagüez Region, with the collaboration of key partners, held the First Breastfeeding Fair in August 2003, reaching 392 persons.
- \*The biennial PRAMS-like Maternal and Child Health Survey (ESMIPR) took place in June 2004. Data analysis is in progress.
- \* The Secretary of Health signed a proclamation declaring the first week of August 2004 as National Breastfeeding Week.
- \* In March 2004, MCH staff members reached 117 persons through a distance learning activity on breastfeeding for health care providers across the Island.
- \*In June 2004, an MCH staff member offered a lecture on Legislation and Governmental Support of Breastfeeding in 2 meetings sponsored by WIC Program, reaching 400 WIC staff members.
- \*Breastfeeding orientation and counseling were provided to 830 women participants of the HVP in calendar year 2003.
- \*A total of 4306 persons took part in 600 group orientations on breastfeeding carried out across PR by MCH Community Health Workers.
- \*In 2003, CHW's offered 43 sessions of the "Comenzando Bien" prenatal curriculum, which includes the topic of breastfeeding, reaching 530 persons.
- \*During FY 2003-2004, The DoH continued its efforts in establishing a public policy to promote breastfeeding in the immediate postpartum period in all hospitals in PR. For this purpose, the MCH Program, the Breastfeeding Committee, and the Secretariat for Regulation and Certification of Health Facilities, collaborated in implementing Law 79 of 2004 that forbids supplying breast milk substitutes to newborns and infants without the mother's consent in all sites where obstetrics and child care services are provided in PR. Public notice of the Law was published in 3 major local newspapers. MCH staff members prepared and distributed educational material regarding the law and breastfeeding to health providers and institutions.

In June 2004, the DoH Breastfeeding Committee coordinator was interviewed by a major local newspaper regarding the implementation of Law 79 mentioned above.

- \*The MCH staff took part in public hearings regarding 2 legislative bills dealing with breastfeeding.
- \*The Breastfeeding Promotion Committee met 6 times during this period.
- \*Eleven perinatal nurses from the MCH Program promoted breastfeeding practices in hospitals across the Island and offered individual counseling.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	mid Serv	Leve	l of
	DHC	ES	PBS	IB
1. Conduct the Maternal and Infant Health Survey (PRAM's like) during the first semester of 2006.				X
2. Share ESMIPR 2006 findings with key providers of prenatal and perinatal services.				X
3. Prepare and distribute a directory of programs and resources that promote breastfeeding in PR.				X
4. Continue enforcing the law that bans use of breast milk substitutes without written consent.				X
5. Enforce the Administrative Order on breastfeeding CME for recertification of health providers.				X
6. Carry out at least 40 courses of "Comenzando Bien" which include the breastfeeding topic.			X	
7. Promote breastfeeding through group orientations at the community level.			X	
8. Increase understanding of the importance of breastfeeding among the participants in the HVP.			X	
9. Cooperate with other partners (WIC, LACTA Project) in their efforts to promote breastfeeding.				X
10. Convene the Breastfeeding Committee at least every other month.				X

### b. Current Activities

Several activities mentioned earlier continue on an ongoing basis during the current year. We want to highlight the following activities:

\*The Monitoring and Evaluation Section of the MCH Division completed the analysis of the data collected through the ESMIPR 2004 regarding breastfeeding in the immediate postpartum period, as well as through a follow-up telephone survey at 6 months postpartum of mothers who participated in the ESMIPR questionnaire. A telephone survey at 12 months postpartum is in progress.

\* In August 2004, the MCH Program in the Mayagüez Region held the Second Breastfeeding Fair with the cooperation of key community partners. A total of 267 persons took part in the event.

\*In alliance with the MCH program, LACTA Project held a press conference at the Governor's residence as part of the Breastfeeding Promotion Week activities, with the participation of a group of mothers from the health regions across the Island who breastfed for at least 6 months.

\*The Department of Health, complying with Law #155 of 2002 that requires the availability of a suitable area for breastfeeding in all public facilities, arranged a room at the Central Offices for staff interested in breastfeeding during working hours. A survey of personnel was conducted via e-mail to identify their needs. The MCH Division furnished the area. A follow-up survey among users is in progress to confirm if their expectations have been met.

\*During calendar year 2004, the CHW's provided 44 sessions of "Comenzando Bien", which includes the topic of breastfeeding, reaching 538 persons in the community. An additional course was carried out by one of our staff members at the DoH for pregnant staff members.

\*The Breastfeeding Committee has met on a regular basis. Its main tasks have been to collaborate in all efforts towards implementing the existing laws that protect mothers' and babies' breastfeeding rights; to promote the Baby Friendly Hospital Initiative in PR; and to continue enforcing the Administrative Order requirement of continuing education on breastfeeding for re-certification of health providers. All these activities are in progress.

\*In collaboration with the MCH Division, LACTA Project, a member of the DoH Breastfeeding Promotion Committee, offered two lectures on breastfeeding issues during the fall of 2004 for health professionals and key community partners.

\*Breastfeeding group orientations have been available at community level across the Island with the distribution of educational material.

\*In October 2004 the MCH Training Program of the School of Public Health, UPR, offered a training course to 24 nurses from the Home Visiting Program to become Certified Lactation Educators. This training was provided with federal funds by HRSA and MCHB.

\*ESMIPR data related to breastfeeding has been shared with many partners.

## c. Plan for the Coming Year

To achieve our objective, we will focus our efforts in the following activities during this coming year:

\*The data collected and analyzed through the PRAMS-like Maternal and Child Survey (ESMIPR) for 2004 concerning breastfeeding and other MCH issues will be shared with health professionals and key policy persons during the Fifth SSDI Conference to be held at two different sites in August and September, 2005. This study, to be repeated during the first semester of 2006, will continue providing useful information related to breastfeeding rates in PR and is an excellent tool to monitor the breastfeeding HP 2010 objectives.

\*The CHW's will provide at least 40 sessions of "Comenzando Bien".

\*The Department of Health will continue its efforts in promoting breastfeeding and use of human breast milk in the immediate postpartum period in all hospitals in PR through the establishment of public policy.

\*The Breastfeeding Committee will evaluate the implementation of Administrative Order #129 by health licensing boards and enforce its observance.

- \* The Breastfeeding Committee will continue meeting at least every other month.
- \*The Breastfeeding Committee will continue collecting information to update and distribute a complete directory of breastfeeding programs and resources to provide adequate services within reach for women and children across the Island.
- \* Eleven perinatal nurses, paid by Title V and on location at local and regional hospital facilities throughout the Island, will foster breastfeeding practices through group orientation and individual counseling, as needed.
- \* The MCH Program will continue collaborating with key partners in the promotion of breastfeeding, such as the activities sponsored by WIC Program and LACTA Project.

Performance Measure 12: Percentage of newborns who have been screened for hearing before hospital discharge.

Tracking Performa [Secs 485 (2)(2)(B)(iii		)(iii)]			
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	1	1	1	5	15
Annual Indicator	2.3	3.1	3.9	6.9	25.4
Numerator	1346	1795	2086	3499	12989
Denominator	59460	57988	52871	50803	51223
Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	50	75	90	90	90

#### Notes - 2002

2002 - The NHEP Program has not been implemented. During the first year after the implementation, seven (7) hospitals will participate in this initiative Island wide. The estimated annual performance objective depends on the date of final implementation expected for December 2003. Puerto Rico is also expected to have a legislative mandate for hearing screening by December 2003. The annual performance objective from year 2004 to 2007 may be revised next year once the NHEP Program implementation takes place in Puerto Rico.

#### Notes - 2003

2003 The NHEP Program has not been fully implemented Islandwide. Currently, there are eight (8) hospitals performing neonatal hearing screenings. With the approval of Law 311 all hospitals with delivery services in PR are starting to plan or implement their neonatal hearing screening programs. There should be a significant increase in neonatal hearing screenings by the end of 2004. The regulations for Law 311 are being written and once completed and approved, should accelerate overall implementation of the program. The estimated annual performance objective depends on the date of final implementation expected for December 2004. The annual performance objectives from year 2004 to 2007 may need to be revised next year once the NHEP Program implementation takes place in Puerto Rico.

#### Notes - 2004

2004 The NHEP Program has not been fully implemented Islandwide. Currently, there are eighteen (18) hospitals performing neonatal hearing screenings. With the approval of Law 311 and its regulation, all hospitals with delivery services in PR are starting to plan or implement their neonatal hearing screening programs. There should be a significant increase in neonatal hearing screenings by the end of 2005. The annual performance objectives from year 2005 to 2009 may need to be revised next year as continued implementation of the NHEP Program takes place in Puerto Rico.

# a. Last Year's Accomplishments

During 2003 the Puerto Rico Universal Newborn Hearing Screening Program (UNHSP) faced

great challenges affecting the implementation of some of the activities as planned. Nevertheless, we have been effective in making progress towards our main goal. The most significant achievement was the approval of a legislative mandate on December 19, 2003 requiring that hearing screening tests be performed to all newborns on the Island before discharge from the hospital. The regulations for the implementation of this Law have been under development since January 2004. In April 2003, the insurance companies under Health Care Reform agreed to reimburse hospitals for the hearing screening tests for all newborns before discharge; a billing code and a reimbursement rate were established for this purpose. A MOU was developed for UNHSP that is actually a contract between the Puerto Rico Health Department and the seven (7) hospitals of the pilot group. It is called "Acuerdo para la realización del cernimiento auditivo a todo neonato antes de ser dado de alta". The seven (7) hospitals of the pilot group have already signed the agreement. During the reporting period trainings were offered for the seven hospitals, one for the group of pilot hospitals and two onsite. Also an initial training for audiologists was offered in March 2003. Brochures for parents, as well as the materials to start the UNHSP in the hospitals, have been reproduced. We continued developing a tracking system, which accommodates our own needs and expectations.

Also during the reporting period we received the technical assistance from MCHB. Various meetings were held to discuss the status and the implementation of the UNHSP in Puerto Rico. The Advisory Committee revised the procedural protocols to accommodate them to the recommendations given to this particular.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra		Leve vice	l of
	DHC	ES	PBS	IB
1. Provide follow-up tracking to 10% of newborns identified with hearing loss.				X
2. Implement the UNHS programs in twenty (20) birthing hospitals.				X
3. Offer training activities on UNHS for participant hospital staff.				X
4. Offer training activities on UNHS for Audiologists, SLP, Nurses and Physicians.				X
5. Collaborate in the development of UNHS programs at all birthing hospitals in Puerto Rico.				X
6. Implement the data tracking system for UNHS.				X
7. Create a UNHS program website to facilitate the delivery of information regarding UNHS and the UNHS program.				X
8. Plan and develop promotional and educational activities to create awareness of UNHS in the general population.			Х	
9.				
10.				

### b. Current Activities

Our main goal this period was to begin full implementation of the UNHSP in the 39 birthing hospitals of the island [including the seven (7) hospitals of the pilot program. In order to accomplish this goal the regulations for the implementation of Law #311 had to be drafted and approved. The UNHS Advisory Committee met numerous times during the year to draft the regulations for Law #311. On January 14, 2005 the regulations were finally approved. This should provide a frame of reference for hospitals developing their UNHS programs and help

hasten UNHS implementation islandwide.

Equipment was delivered and on-site training was offered to the hospital staff of the UNHS pilot program of seven (7) hospitals. We collaborated with the Academy of Audiology of Puerto Rico to present information about the program to its members.

The development of the electronic data collection system is well underway and we should be able to begin implementation of the data system early in 2005. Regular data collection has continued and we had observed an increase in the number of newborns screened at the end of 2004. During year 2004, eighteen (18) hospitals were screening births for hearing loss. For this period, a total of 12,989 births were screened for hearing loss, accounting for twenty five percent (25%) of all births in Puerto Rico. This year we have applied for a three-year federal grant through the Department of Health and Human Services Health Resources and Services Administration to continue funding the activities of the UNHSI Program during fiscal year 2005.

# c. Plan for the Coming Year

During next year our main goal is to continue islandwide implementation of the UNHSP and begin implementation of follow-up services for identified newborns. Through promotional and educational activities we expect to increase awareness of the UNHSP in the general population and health care providers including physicians, nurses, audiologists and speech and language pathologists, among others.

We expect to begin implementation of our electronic tracking system. The DHS Information System Administrator developed this system in collaboration with members of the UNHS Advisory Committee.

Activities under consideration for this year include:

- \* Improve follow-up procedures to ensure linkage to early intervention programs including amplification.
- \* Improve billing and collection for the hearing screening services.
- \* Orientation about UNHS to private agencies and public forums.
- \* Create awareness among families about the UNHS program and its costs.
- \* Organize and implement a public awareness campaign on the importance of the UNHS.
- \* Create a UNSHP web site with information for hospitals, health care providers and the general public.
- \* With the support of professional organizations related to audiologists, study the need for and opinions regarding a pediatric audiologic evaluation certificate.
- \* Develop Parent Advisory and Support groups.
- \* Identification of new funding sources.

#### Performance Measure 13: Percent of children without health insurance.

Tracking Performa [Secs 485 (2)(2)(B)(iii					
Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance		2	2	1	1

Objective					
Annual Indicator	0.4	0.3	0.4	1.1	1.3
Numerator	5474	3468	3432	15012	15136
Denominator	1216450	1156022	903025	1364807	1164353
Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	1	1	1	1	1

### Notes - 2002

For fiscal year 2002, the estimate was done using the Head Start health insurance population experience. Among the 33,575 Head Start children enrolled in the program, only 0.38% did not have a health insurance plan. We assume that Head Start children would be representative of all low income children in Puerto Rico.

Denominator: 2001 Population Estimates from Planning Board.

Since the Head Start population is one of low socioeconomics status we consider that they represent the rest of the children regarding this performance measure.

#### Notes - 2004

The estimate for this performance measure was done using the Head Start health insurance data. According to this data, a total of 450 (1.3%)children did not have a health insurance plan. We assume that Head Start children are low income children in Puerto Rico. They represent the maximum number of children without health insurance. The denominator was the population estimation as of July 2004 and was obtained from the US Census Bureau.

# a. Last Year's Accomplishments

The estimated number of children and adolescents 0-19 years old was 1,164,353 as of July 2004. Of these, a total of 599,177 (39.4%) held the government insurance plan by December 2004. As mentioned elsewhere, Puerto Rico finished the implementation of the HCR in July 2000.

Among the goals of the HCR was to assure equal access to quality services to all citizens through a government paid health insurance plan for the low-income population or a third party payor. Otherwise, health services must be paid out of pocket.

Within the new health care environment resulting from the implementation of the HCR, the role of the Title V program consists in identifying those children without health insurance, providing orientation at the community level and referring them to the Medicaid program for evaluation and certification. During the reporting period, a total of 98 small group orientations reaching 1,146 individuals across the Island were documented.

In estimating the proportion of children without health insurance we use the experience with Head Start children. This is a low-income population that can be used as a proxy to estimate the number of children without health insurance across the Island. Indeed, an evaluation of the health coverage of 35,299 preschool children enrolled in the Head Start Program during FY 2004-2005 demonstrated that 79.8% held the GIP; nineteen percent (19.0%) had a private health plan; and only 1.3% (450) did not have a health insurance plan.

Based on the above findings we estimate that approximately 15,136 children and adolescents do not hold a health insurance plan. This is the target population for our outreach activities.

Performance Meservice paid by the Tracking Perform [Secs 485 (2)(2)(B)(0) Annual Objective and Performance Data	e Medicaid Prog ance Measure:	<i>gram.</i> s	entially Medicaid	d-eligible childre	2004	eceivea
service paid by the Tracking Perform	e Medicaid Prog ance Measure:	<i>gram.</i> s	ntially Medicaid	d-eligible childre	en who have re	eceivea
		•	ntially Medicaid	d-eligible childre	en who have re	eceivea
c. Plan for the C Ongoing outreach government admi Evaluation Comm the Evaluation Co concerns and sug report in August 2 regarding the HC measure.	activities for the listration, the lission convenermission concepts gestion regard 005. By that tir	Health Care I ed by the gov ducted public ing the health me, the progr	ear as mentione Reform is unde vernor. During t hearings in dif h care reform. I	ed in 13b. As pa r the evaluation he months of Ma ferent areas of t It is expected to clear vision of t	rt of the new of a special arch and April the Island to id have an evalu he new policie	2005 lentify uation
			ana 10101 anoo	in need to the i	Medicaid Prog	pe of ram.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

**Activities** 

2. Assess the impact of the Evaluation Commission Recommendations of

1. Conduct outreach activities to identified children without health

insurance and refer them to Medicaid.

the HCR in the MCH population.

b. Current Activities

3. 4. 5. 6. 7. 8. 9. 10. Pyramid Level of **Service** 

DHC ES PBS IB

X

X

Annual Performance Objective	0	0	0	0	0
Annual Indicator	NaN	NaN	NaN	13.3	16.5
Numerator	0	0	0	61523	98891
Denominator	0	0	0	462586	599177
Is the Data Provisional or Final?				Provisional	Final
	2005	2006	2007	2008	2009
Annual Performance		17	16	15	14

### Notes - 2002

Not applicable because the Puerto Rico Medicaid Program has a cap. It is unfair to compare Puerto Rico with the rest of the States regarding this performance measure.

#### Notes - 2003

Puerto Rico uses close to \$1,208 million to purchase the GIP for low-income persons under 200% of the FPL. Medicaid dollars represent only 13.25% (\$160 million) and SCHIP funds 2.4% (\$29 million). The budget used to purchase the GIP for low-income individuals is a combination of state and local funds (municipal), Medicaid and SCHIP. We are using as a proxy for this PM the total of infants, children and adolescents with the GIP who received at least one service during FY 2002-2003. The data presented was provided by the PR Health Insurance Administration (ASES).

### Notes - 2004

This performance measure was estimated using as numerator the total number of children 0-19 years old who received EPSDT services throught the GIP, and the denominator was the number of children 0-19 years of age holding the GIP. The data was provided by the Health Insurance Administration.

# a. Last Year's Accomplishments

It is important to highlight that Puerto Rico should not be compared with the states regarding this performance measure. Puerto Rico is under a cap regarding the allocation of Medicaid funds. Medicaid funds are used to complement state monies allocated to buy the GIP for clients certified by the Medicaid Program. In 2003-2004, Medicaid funds represented only 12.1% of the total budget required by the GIP. As reported by ASES, a total of 98,891 children between birth and 19 received EPSDT services. This figure represents about 16.5% of children enrolled in the GIP. It has been assumed that this is the proxy for Medicaid eligible in PR.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	Pyramid Level of Service				
	DHC	ES	PBS	IB		
1. To promote the availability of the GIP for low-income children.			X			
2.						
3.						

4.		
5.		
6.		
7.		
8.		
9.		
10.		

### b. Current Activities

The MCH role consists on promoting the availability of the GIP for low income children under 200%. This activity is carried out at the community level through the Home Visiting Services and outreach activities.

# c. Plan for the Coming Year

As mentioned earlier, Puerto Rico is under a Medicaid cap. We expect that the current situation with the budget at the federal level will not affect us even more.

Performance Measure 15: The percent of very low birth weight infants among all live births.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	1.1	1	1	1	1		
Annual Indicator	1.4	1.3	1.4	1.4	1.5		
Numerator	854	744	747	716	762		
Denominator	59460	55983	52871	50803	51223		
Is the Data Provisional or Final?				Final	Provisional		
	2005	2006	2007	2008	2009		
Annual Performance Objective	1.4	1.3	1.2	1.1	1		

### Notes - 2002

Numerator and denominator are from birth data file provided by Office for System Development.

# a. Last Year's Accomplishments

The two determinant factors for high rates of infant mortality in Puerto Rico are very low birth weight and prematurity. There is a wide variety of contributing factors which are resistant to

traditional medical care. These include, but are not limited to, factors associated with behaviors such as smoking, alcohol consumption, illicit drug use, stress, domestic violence, inadequate weight gain during pregnancy as well as multiple births.

During the reporting period we documented 2,024 educational activities reaching 23,034 pregnant women that may contribute to the prevention of this poor birth outcome. The topics included in these educational activities were: 1) Effects of smoking, alcohol and illicit drug use during pregnancy; 2) Adequate nutrition in pregnancy; 3) Identification of signs and symptoms of preterm delivery; 4) Gingivitis during pregnancy; 5) The importance of prenatal care; and 6) "Comenzando Bien" prenatal care course. Almost all these activities are reinforced with appropriate educational materials.

In addition, the Home Visiting Program served 10,703 pregnant women, infants (0-24 months) and children with complex medical and social risk factors. All pregnant women were properly screened for smoking, alcohol consumption, illicit drug use, domestic violence and perinatal depression. Those women found positive for any of these risk factors were given education and counseling by the Home Visiting Nurse and appropriate referrals were filled for diagnosis and treatment as required.

On the other hand, the WIC Program served an average of 15,639 pregnant women with nutritional risk factors.

The MCH program conducted continued education activities for our Home Visiting Nurses as well as for private perinatal providers. These activities were aimed at increasing the awareness regarding the issue of the high proportion of births of VLBW infants, as well as to develop their skills for the identification and management of pregnant women at risk of giving birth to a very low birth weight baby.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities		Pyramid Level o Service			
	DHC	ES	PBS	IB	
To provide Home Visiting services to about 7,000 pregnant women with medical and social risk factors.		X			
2. To provide CME activities to Home Visiting Nurses and prenatal care providers to enhance their skill in identifying women at risk having a LBW.				X	
3. Raise awareness among the public at large of the importance of early prenatal care.			X		
4. Provide about 50 courses of "Comienzo Saludable".			X		
5. Disseminate educational materials regarding the negative effect of smoking, alcohol consumption and drug used during pregnancy.			X		
6. Refer to the WIC program pregnant women identified with nutritional risk factors.		X			
7. Provide educational activities at the community level covering different topics that contribute to LBW.			X		
8.					
9.					
10.					

b. Current Activities

During the current year (2004-2005), most of the activities mentioned earlier are being conducted on an ongoing basis. The Home Visiting Program (HVP) is aimed at reducing the determinant factors of infant mortality: LBW and prematurity. It has been serving high-risk pregnant women across the Island in 95% of the municipalities. All pregnant women enrolled into the HVP receive a comprehensive health assessment. The assessment includes screening for tobacco, alcohol and drug use, which are behavioral risk factors contributing to low birth weight and prematurity; in addition to sociodemographic factors, medical and obstetrical complications. Following the assessment, all pregnant women participants of the HVP are appropriately educated/counseled and referrals are made for identified needs. As of December 2004, a total of 106 Home Visiting Nurses were providing services across the Island.

A "warning signs of premature labor" message board was disseminated to inform all pregnant women. This educational material is provided not only to HVP participants, but also to non-participants reached through a variety of educational activities at the community level.

Another risk factor that is being associated with preterm birth is poor oral health. During this year we began to emphasize the importance of oral health services during pregnancy. In collaboration with the Director of the Oral Health Services Division we conducted two presentations entitled "Preventing Prematurity through Oral Health Services". One presentation was geared to the Healthy Start Consortium and the other to MCH personnel (Home Visiting Nurses, CSHCN) and the staff of collaborating programs.

# c. Plan for the Coming Year

As stated elsewhere, a VLBW infant is an outcome of a broad number of risk factors that may lead to a premature delivery. These factors include chronic health conditions, obstetric complications, multiple births, behavioral risk factors such as smoking, alcohol consumption, illicit drug use, domestic violence and stress, low BMI at the time of conception and short intergenesic periods, among others.

A comprehensive prenatal history and a thorough physical examination are the best tools that help in the identification of most pregnant women at risk of premature delivery. The intervention should be tailored according to the identified risk factors associated with prematurity and VLBW babies.

It is expected that the Home Visiting Nurses will serve about 5,000 high risk pregnant women through case management and care coordination for needed services aimed at reducing poor pregnancy outcomes. In addition, about 7,000 postpartum women will receive services aimed at increasing the interconceptional period to at least 24 months. This is another strategy aimed at decreasing unintended pregnancy and LBW.

During 2005-2006, we will continue our efforts in collaboration with the Division of Oral Health creating awareness about the importance of oral health services during pregnancy, not only among pregnant women but also among prenatal providers and oral health professional as well.

Performance Measure 16: The rate (per 100,000) of suicide deaths among youths aged 15 through 19.

Tracking Performa [Secs 485 (2)(2)(B)(iii			
Annual Objective and			

Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	5	4.5	4	3.5	3
Annual Indicator	3.2	3.9	4.2	4.6	4.3
Numerator	10	12	13	14	13
Denominator	313436	309926	309926	301435	299286
Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	2.5	2	1.5	1	1

### Notes - 2002

Numerator is from death data file provided by Office for System Development. Denominator is an estimate provided by the Puerto Rico Planning Board.

## a. Last Year's Accomplishments

The MCH Division developed a report about the health conditions of the adolescent population ages 10 to 19 that include a section on suicidal behavior. According to the report, suicide is the third leading cause of deaths for adolescents in Puerto Rico. From 1990 to 2001, 189 adolescents ages 10-19 committed suicides, comprising 4.8% of all reported suicides in Puerto Rico. Over the past decade, suicide rates have remained relatively stable, fluctuating slightly for the age group 15-19. Males commit suicide much more frequently than females and tend to utilize firearms and hanging as a means to terminate their lives. Data gathered by YRSB reveal that in a ten-year period (1991-2001) an increasing number of adolescents of both sexes have attempted suicide requiring medical assistance.

The Department of Health sponsored the First Conference on Adolescent Mental Health held on March 30, 2004. The conference gathered a group of experts and researchers that addressed relevant mental health issues affecting the adolescent population in Puerto Rico. Five hundred persons from diverse human service fields attended the conference.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
		ES	PBS	IB	
1. Continue analyzing available VS and other sources of data on suicide by geographical areas.				Х	
2. Establish a collaborative relationship among state agencies (Family, Education and Health) to address the issue in the public school system.				Х	
3. Increase teen and parents awareness of the signs associated with suicide intention using educational materials.			X		
4.					
5.					

6.		
7.		
8.		
9.		
10.		

### b. Current Activities

The Commission for Suicide Prevention of the Department of Health - composed of state agencies and non-profit non-government agencies - carries out activities to promote public awareness on suicide as a public health issue and ways to detect suicidal behavior. Among the activities carry out by the Commission are the National Suicide Prevention Week (August) and Christmas Suicide Alert (December).

The Administration of Mental Health and Anti-Addiction Services (ASSMCA, Spanish acronym) is in the process of reviewing the final report of the "Abracemos La Vida" a pilot project on suicide prevention in the school system. The Comprehensive Adolescent Health Services carried out the pilot project. The main objective of the pilot project was to train schools gatekeepers in the public school system on early identification, initial management and referrals of students showing suicidal behaviors.

# c. Plan for the Coming Year

In order to address the problems of adolescent suicide behavior, the Comprehensive Adolescent Health Services of Puerto Rico MCH will collaborate with the Administration of Mental Health and Anti-Addiction Services (ASSMCA), the Department of Education and the Commission for Suicide Prevention in developing strategies to prevent adolescent suicide in the public school system. The final report of the "Abracemos la Vida", a pilot project on suicide prevention and postvention undertaken by the Comprehensive Adolescent Health Services Program will be disseminated among schools that participated in the project.

Performance Measure 17: Percent of very low birth weight infants delivered at facilities for highrisk deliveries and neonates.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	90	76	77	78	79		
Annual Indicator	82.2	70.9	66.1	41.8	45.5		
Numerator	702	526	494	299	340		
Denominator	854	742	747	716	747		
Is the Data Provisional or				Final	Provisional		

Final?					
	2005	2006	2007	2008	2009
Annual Performance		60	65	70	75
Objective					

### Notes - 2003

Data for this performance measure is provided by ODSI. They inform us the number of VLBW babies born by facility across the Island. We identify the number of facilities which may comply with the criteria for Level III. The explanation that we have for the wide variation of the percentage of LBW babies born at Level III facilities across the years is that some facilities may provide level III services in one year and not in another. Also, as a result of the implementation of the Health Care Reform, the low income population may choose the facilities where they want to go for delivery. This situation results in very wide changes not only in the number of births per facility from year to year, but also where the VLBW babies are delivered. This information is important in order to appropriately provide information to pregnant women at risk of preterm delivery.

#### Notes - 2004

A panel of experts in neonatology of the Pediatric University Hospital provided us with a list of Level II and Level III NICUS available in the Island. Only four (4) level III NICUS were identified and are located at:

1) Pediatric University Hospital (PR Medical Center), 2) Municipality Hospital of San Juan (also located at the PR Medical Center - San Juan), 3) Hospital Auxilio Mutuo (San Juan), and Hospital Interamericano de Medicina Avanzada (Caguas).

# a. Last Year's Accomplishments

Data related with the place of birth of VLBW babies in 2003 was analyzed and the information was shared with concerned parties. All Home Visiting Nurses routinely assessed their clients for risks associated with premature delivery. They provided appropriate education/counseling regarding the signs and symptoms associated with premature labor. The nurses provided information to their clients regarding the closest birthing facility that provides level III perinatal services. To reinforce the message, a culturally sensitive magnetic board explaining the signs of premature labor and what to do in the situation was distributed to HVP participants and in the community.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Educate pregnant women of the risks of preterm delivery and where to go in case of an emergency.			X		
2. Disseminate educational materials explaining signs and symptoms of PTB.			X		
3. Analyze place of birth and outcome of all VLBW infants born in 2003.				X	
4. Disseminate findings of activity #3 among obstetricians and neonatologists.				X	
5.					
6.					
7.					
8.					

9.		
10.		

### b. Current Activities

During the current year, the Home Visiting Nurses have continued emphasizing the orientation regarding the signs and symptoms of preterm delivery among Healthy Start (HS) participants. In addition, the culturally sensitive magnetic board containing information aimed at creating awareness on this issue is provided to HS participants to reinforce the verbal information. This educational material is disseminated at the community level to all pregnant women reached out in health fairs and other activities.

In November 2004, in collaboration with the PR Chapter of March of Dimes we celebrated Prematurity Awareness and Prevention Day. This activity was widely covered by radio, TV and newspapers of wide circulation. The MCH staff made two presentations. One presentation summarized the most recent data concerning the Maternal and Infant Health Status, and the other discussed the impact of maternal smoking behavior on LBW and maternal-child health.

# c. Plan for the Coming Year

In the coming year it is imperative to continue our efforts in educating pregnant women on the need for self-identification of early signs and symptoms of premature delivery and the location of Level III facilities in case of need.

Besides, it is important to raise awareness among prenatal care providers about this perinatal system problem in Puerto Rico. Women with threat of premature labor must be transferred to Level III facilities on time.

In FY 2005-2006, we plan to conduct a descriptive analysis of all VLBW infants born in 2003. The purpose of the study is to identify the outcome of the baby according to the place of birth. The findings of the study will be shared with perinatal providers and executive directors of birthing facilities across the Island.

Performance Measure 18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	80	82	83	84	85	
Annual Indicator		79.1	80.9	82.1	83.2	
Numerator	46238	44275	42771	41728	42594	
Denominator	59460	55983	52871	50803	51223	

Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	86	87	88	89	90

#### Notes - 2002

Numerator and denominator are from birth file data provided by Office for System Development.

## a. Last Year's Accomplishments

Early, regular and comprehensive prenatal care is one of the most cost-effective public health strategies to promote the health and well being of the mother and infant dyad. In Puerto Rico, prenatal care is available through private health plans and the GIP. As a matter of fact, in 2003 of all women who had a live birth; 63.9% were covered with the GIP and 34.2% with a private health plan. Only 1.8% did had a health plan. However, this large proportion of pregnant women with a health insurance does not means prompt access to prenatal care. There are system barriers as well as personal barriers that impede early entrance into prenatal care.

During the reporting period we used data from IISMI 2002 and 2003 to raise awareness among stakeholders of the percentage of first trimester admission rate into prenatal care across different geographical areas.

A total of 714 group education activities reaching 12,659 participants were conducted to promote early and continuous prenatal care throughout the Island.

On the other hand, the Healthy Start Project emphasized in outreach activities aimed at pregnant women not connected to a primary provider. The community health workers and home visiting nurses continually stressed the importance of early and continuous prenatal care. Their orientations were complemented with the distribution of educational materials about the importance of early prenatal care.

However in spite of our efforts aimed at increasing the first trimester admission rate we are still behind the set target (90%) established for the year 2010. In 1992, the first trimester admission rate was 75.4% compared to 82.1% in 2003. Because of this we carried out a study aimed at the identification of the reasons for late or no prenatal care in PR.

Figure 4a, National Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service			
		ES	PBS	IB
1. Increase public awareness on the importance of early prenatal care.			X	
2. Provide free comprehensive prenatal care to pregnant women with incomes 200% below the poverty level.	х			
3. Conduct outreach activities directed at early enrollment into prenatal care.		X		
4. During HVP visits to participating families, promote preconceptional care and family planning.	X			
5. Provide free contraceptive methods to GIP participants.	X			

6. Disseminate findings of the study aimed at the identification of late or no prenatal care to key stakeholders.		X
7. Revise and obtain the endorsement from the new Secretary of Health and the Executive Director of ASES on current public policy requiring that pregnant woman receive PNC services upon request.		X
8. Promote compliance with this policy (#7).		X
9.		
10.		

### b. Current Activities

Currently, most of the activities mentioned in previous section are being conducted on an ongoing basis. In addition, a survey among recent mothers who initiated prenatal care after the first trimester of gestation was carried out. The main objective of this survey was the identification of reasons for late prenatal care. A self-administered questionnaire was distributed among recent mothers with history of initiation of prenatal care after 13 weeks of gestation in 33 hospitals across the Island. The results of this study revealed two types of reasons: personal and system barriers. Among surveyed mothers, 96.6% initiated prenatal care after the first trimester and 3.4% had not prenatal care at all.

Surveyed women said that the reasons for seeking care after the first trimester were (1) 64.7% did not know were pregnant; (2) 21.1% did not have a health insurance plan at the time of conception; (3) 15.8% were afraid to inform their parents about their pregnancy; and (4) 9.8% had transportation problems. On the other hand, 41.5% of them had to wait between one and over four weeks for an appointment after they have decided to seek prenatal care.

Most of the surveyed women were single, low-income, unemployed and beneficiaries of the GIP. It is important to mention that a significant proportion of them did not have planned this pregnancy.

# c. Plan for the Coming Year

During the next fiscal year the MCH staff main efforts will be directed to the dissemination of the findings of the study described in the previous section among concerned partners. These include the regional MCH Directors and health educators, medical directors of the health insurance companies, the Director of the Administration of the Health Insurance and others.

Outreach activities and community education will be tailored based on the findings.

Due to the changes in leadership of the DoH and ASES, the public policy aimed at admitting the woman into prenatal care as soon as she request the services must be revised for endorsement of the Secretary of Health and the Executive Director of ASES. After that it will be disseminated to the network of prenatal care providers across the Island.

### D. STATE PERFORMANCE MEASURES

State Performance Measure 1: The number of HIV positive pregnant women treated with AZT.

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	100	100	100	100	100		
Annual Indicator	97.4	97.4	94.2	95.7	82.5		
Numerator	76	74	81	67	66		
Denominator	78	76	86	70	80		
Is the Data Provisional or Final?				Final	Provisional		
	2005	2006	2007	2008	2009		
Annual Performance Objective	100	100	100	100	100		

#### Notes - 2002

Data provided by the Pediatric HIV/AIDS program.

### Notes - 2003

Data provided by the Pediatric HIV/AIDS program.

#### Notes - 2004

Data provided by the Pediatric HIV/AIDS program.

# a. Last Year's Accomplishments

Since the establishment of a public policy in 1994 to provide pre-counseling, testing and treatment with ZDV to all pregnant women with positive HIV results on a voluntary basis, the Department of Health has maintained a close monitoring of all efforts towards this goal. Particular consideration has been given to make AZT available for all women identified and who needed therapy regardless of their economic status.

The Perinatal HIV Guidelines were made available to health insurance companies by the administrative component of the Health Reform to be included in their contracts; these, in turn, sent the information to their system of health providers.

As a strategy to identify women at risk and guarantee treatment to those with positive HIV results, in 2002 the Perinatal HIV/AIDS Prevention Program implemented a pilot project at the University of PR Hospital in Carolina to perform rapid HIV testing to patients admitted to labor room without evidence of being screened during pregnancy. During 2003, a total of 74 women who had no prenatal HIV screening were offered the Oraquik test; seventy three (73) of them agreed to be tested.

Likewise, in a continued collaborative effort with the Perinatal HIV/AIDS Prevention Program to assure that all pregnant women receive counseling for HIV prevention, testing, and treatment of positive cases, 70 pregnant women were found positive for HIV and received treatment during FY 2003- 2004.

During 2003, prenatal orientation and counseling related to the importance of HIV prevention was provided to all (3163) pregnant participants of the Home Visiting Program; referral for evaluation was offered to those who had not been tested.

During FY 2003-2004 a total of 1792 persons participated in 108 orientations on the topic of HIV/AIDS across the Island carried out by Community Health Workers of our MCH Program.

In October 2003, the PR DoH, in alliance with CDC and Region II STD/HIV Prevention Training Center, sponsored an educational activity to present updated HIV/AIDS information related to PR to primary health providers and outreach personnel island wide.

A total of 65 health providers, among them physicians, nurses, health educators and others, received continuing education on the subject of perinatal HIV/AIDS prevention and treatment during the First Forum on Chronic Diseases of the Americas and the Caribbean celebrated in June, 2004.

Outreach personnel of the HIV/AIDS Prevention Program offered 107 HIV pre- and post-counseling activities across the Island during 2003. Of these, twenty two (22) were offered by perinatal outreach staff, reaching 744 women.

The ZDV Therapy Advisory Committee conducted site visits to health regions as well as a close monitoring of the observance of the guidelines. During this period the Program visited five regional hospitals, providing educational update on the subject to 121 health providers.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	mid Serv	Leve vice	of
	DHC	ES	PBS	IB
1. Provide information on the importance of HIV testing to participants of Home Visiting Program.		X		
2. Offer continuing education on universal prenatal HIV screening and follow up to health providers.				X
3. Carry out HIV prevention activities at detoxification centers and drug shooting alleys for women at risk.		x		
4. Provide adequate evaluation, counseling, and treatment to HIV positive pregnant women.	X			
5. Share data of results of perinatal HIV testing and treatment with key health providers.				Х
6. Support HIV screening and counseling of all pregnant women by Perinatal HIV Prevention Program.	X			
7. Disseminate educational material about perinatal HIV prevention at the community level.			X	
8.				
9.				
10.				

#### b. Current Activities

Most of the activities mentioned in section 1(a) continue on an ongoing basis. We want to give special attention, nevertheless, to the following:

\*During 2004, a total of 104 pre- and post- counseling activities were provided by outreach personnel of the HIV/AIDS Prevention Program throughout the Island. Of these, 29 orientations were given by perinatal outreach staff, reaching 873 women of reproductive age.

- \*Likewise, MCH Program CHW's personnel have continued providing orientation on the subject of HIV/AIDS prevention throughout the Island.
- \*During 2004 the participants of the Home Visiting Program (5162) received prenatal orientation and counseling regarding HIV prevention.
- \*Collaborative efforts between the MCH and the Perinatal HIV/AIDS Prevention Programs have continued to guarantee that all pregnant women receive HIV prevention counseling, testing, and adequate treatment to those found positive on a voluntary basis. During 2004, 80 pregnant women were detected with HIV positive results. Of these, 66 (82.5%) received antiretroviral medications. Only two of the 79 children delivered were found HIV positive.
- \*Rapid HIV analysis through the Pilot Project mentioned in section (a) was offered to 135 women in labor at the UPR Carolina Hospital without evidence of prenatal HIV testing and 134 accepted being evaluated. Two (2) pregnant women were found positive.
- \*On June 3, 2005, a total of 29 Home Visiting Nurses and perinatal nurses from our MCH Program participated in a training activity on the subject of Prevention and Treatment of Perinatal HIV/AIDS, sponsored by St. Francis Xavier University of New Jersey, with the collaboration of the PR Department of Health, and other key partner entities.

# c. Plan for the Coming Year

In order to pursue our objective of identifying HIV positive pregnant women and providing them treatment with AZT, the MCH Program will continue providing support to those activities that have been effective toward this goal. The following activities will be our main target for the coming year:

- \*Continue supporting all efforts of identifying pregnant women that lack prenatal HIV testing through the Rapid HIV testing Pilot Project during 2005-2006.
- \*Continue providing adequate evaluation, counseling and treatment to all HIV positive pregnant women throughout the Island.
- \*Continue offering individual prenatal education to all women participants of the Home Visiting Program on the subject of HIV prevention, testing and adequate treatment of those with positive results.
- \*Offer continuing education activities that deal with issues regarding the need for universal HIV screening and intervention during the prenatal period to primary health providers throughout the Island, in collaboration with health insurance companies.
- \*Perform outreach activities at key places such as Detoxification Centers and drug shooting alleys to provide counseling on HIV prevention to women of reproductive age found in those areas.
- \*Carry out an educational activity covering issues of health care and follow-up of pregnant patients with HIV/AIDS aimed at obstetricians-gynecologists and pediatricians across the Island.
- \*Disseminate educational materials at the community level island wide on the topic of perinatal HIV prevention.

Based on the needs assessment for the next cycle we need to continue the tracking of this performance measure.

State Performance Measure 2: Establish a Home Visiting program in at least 90% of the Island by the year 2,000.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	90	95	95	95	95	
Annual Indicator	89.7	87.2	92.3	85.9	94.9	
Numerator	70	68	72	67	74	
Denominator	78	78	78	78	78	
Is the Data Provisional or Final?				Final	Final	
	2005	2006	2007	2008	2009	
Annual Performance Objective	95	95	95	95	95	

#### Notes - 2003

Reported data as of December 31, 2003.

## a. Last Year's Accomplishments

The core program of the Puerto Rico Title V program is the Home Visiting Program. Its target population consists of pregnant women and children up to 2 years of age with complex health and social problems. During calendar year 2004, 122 Home Visiting Nurses (HVNs) provided services in 75 out of 78 municipalities and 84 Community Health Workers (CHW) were assigned in 63 municipalities. During this period, 6,500 families received home visiting services. In addition, The HVNs and CHWs reached over 15,000 persons in the community through group orientations on diverse topics related to maternal and child health.

The HVNs and CHWs participated in various types of continuing education activities, including training sessions, workshops and distance education via satellite television. These training activities are sponsored by the PR Healthy Start Project and Title V to continue to develop their professional capacity to deliver quality services to the population. The topics included Effective Planning of Educational Activities, Motivation for Work, Oral Health in Pregnancy, Perinatal Health, Update on Pediatrics, Father's Involvement in Childrearing, and Effective Communications. The Outreach component within the MCH Division was also redesigned to complement HVP services. The role of the Community Health Workers is focused on identifying pregnant women with no prenatal care and infants who are not receiving preventive pediatric care, to be referred to the HVP and/or to prenatal or pediatric care services available in the community. Each CHW maintains an extensive directory of resources that exist in the community and how to access them, which they share with the HVNs to facilitate the referral

and care coordination efforts.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Recruit home visiting nurses for the municipalities lacking this service.				X	
2. If fiscally feasible, recruit additional nurses for municipalities with greatest need.				X	
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

#### b. Current Activities

Home Visiting Nurses continue to provide case management/care coordination services to pregnant and parenting women (up to 24 months after delivery), and children up to 24 months of age. According to Healthy Start Initiative guidelines, emphasis is given to increasing the use of preventive services, including early admission to prenatal care, regular pediatric and women's health visits to primary providers, and adequate immunizations; screening for behavioral risk factors and maternal depression and addressing women who are at risk or engaging in risk behaviors through educational interventions by the HVNs or referrals to treatment services available in the community; and promoting family planning, contraceptive use and an interconceptional period of at least 24 months after birth. HVNs have a caseload of 50 families each. This allows them to dedicate sufficient time to each family to ensure quality services. CHWs will continue to carry out outreach activities to identify pregnant women and children who are not connected to the health care system. They refer potential participants to the HVP or to services available in the community, according to their needs and the capacity of the local HVN to admit new cases. They will also continue to assist HVN in their interventions, offering follow up to clients when required.

During the current year HVNs and CHWs will again receive continuing education on MCH topics. We are in the process of performing a training needs assessment to determine the topics. The focus of the training is on identifying and managing those risk factors that have the greatest impact on preterm births, LBW and other poor birth outcomes.

Providing Home Visiting services in all municipalities continues to be a great challenge. Several barriers have prevented us from achieving this goal. The first one has been the aging population of Home Visiting Nurses. Many of our HVN have completed 30 years of public service and are therefore eligible for retirement. Recruiting new ones is difficult due to the nursing shortage and the long bureaucratic process required to fill a vacant position. There is also a need to allocate funds to assign an adequate number of Home Visiting Nurses to each municipality according to the local demand for HVP services. As a result, we continue to have an insufficient number of nurses. As of June 2005, there are 122 HVNs working in 75 of the 78 municipalities in Puerto Rico (96.2%).

Beginning in 2005 we are taking over the HVP for the Municipality of San Juan (MSJ), which was previously administered by the MSJ Health Department. This will be done through a collaborative effort, whereby we will provide the HVNs, CHWs, a Health Educator and a Coordinator, and they will provide office space in the MSJ Health Centers. Five HVNs and one CHW will provide direct services to the MCH population in the MSJ. They have undergone the initial training to ensure they provide the same level of service and follow the care protocols.

# c. Plan for the Coming Year

The HVP will continue to provide services at a rate of 50 participant families per HVN. The quality of services and their impact on the health and well being of pregnant women, their infants and families will be closely monitored during the year. The evaluation component has been strengthened and the local supervisory role increased. Community Health Workers will continue to carry out outreach activities to identify pregnant women and children who are not connected to the available health care system, as described in the previous section. Filling the vacant HVN positions will continue to be a priority. Candidates have been identified for many of the vacant positions, and the recruitment process has been initiated. One of the hardest positions to fill has been that of the HVN for the island municipality of Vieques. We have finally been able to identify a candidate who is interested and qualified, and she is undergoing the process of being appointed to the position.

Since 2002 the PRDH has been undergoing a restructuring of its human resources structure. Regular and transitional positions are being created for many of the professionals currently working under contract, if their job description fills the requirements of a regular position. In July 2004, most transitional employees were converted to regular positions. This has created a backlog in the Human Resources office, which in turn causes delays in the process of selecting and evaluating candidates and filling the positions. We will continue to work with the Human Resources office to fill these positions.

Based on the needs assessment for the next cycle we need to continue the tracking of this performance measure.

# State Performance Measure 3: The incidence rate of neural tube defects (NTD's)

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	8	7	6	5	4		
Annual Indicator	6.5	7.2	7.1	4.1	5.2		
Numerator	39	41	38	21	27		
Denominator	60107	56567	53437	51351	51760		
Is the Data Provisional or Final?				Final	Provisional		

	2005	2006	2007	2008	2009
Annual					
Performance	4	3	3	3	2
Objective					

#### Notes - 2002

Numerator provided by the Congenital Anomalies Registry of PuertoRico.

Denominator obtained from birth data file provided by the Office for System Development.

The annual perforance objective were revised for the years 2003 through 2007.

#### Notes - 2003

The numerator is provided by the Congenital Anomailes Registry of Puerto Rico. The denominator is obtained from birth data file provided by the Office for System Development. The incidence rate for year 2003 is provisional, therefore the Annual Performance Objective was not changed. One health region is not considered in the numerator. Final data will be available by August 2004.

The annual performance objectives remained the same for years 2004, 2005 and 2007. The annual performance objective for years 2006 was revised to 3 cases per 10,000 live births.

## a. Last Year's Accomplishments

During FY 2003-2004 we conducted a wide array of population based activities directed at the general public to raise awareness about the importance of folic acid consumption for the prevention of NTDs. In addition, the staff responsible for the promotion of folic acid was very productive in training health professionals and teachers to increase their competence to include folic acid prevention messages in their service provision practices and classrooms.

A total of 75 educational activities were held, with the participation of 15,144 individuals. In October 2003, 10,300 FA prevention kits were distributed in drugstores and supermarkets by health professionals trained to deliver appropriate FA messages. This was made possible by a donation of 13,000 bottles of folic acid by our partners. A media tour was conducted, including TV presentations and radio spots and public service announcement.

The Department of Education collaborates through the inclusion of folic acid prevention messages in the public school health curriculum for the junior and senior high school. Approximately 300 health teachers were trained and provided with instructional modules and educational materials, including an educational video.

At the level of infrastructure building, it is important to highlight the following activities: (1) A survey of 700 WRA was conducted to explore FA related behavior. In addition, focus groups were carried out. Among the reasons for not taking folic acid, participants stated: "I don't need them", "I forget" and "No particular reason". (2) About 300 health professionals were trained, including health educators of the health insurance companies, MCH and WIC program personnel, and CBO and hospital staff. (3) The Third Folic Acid and Birth Defect Symposium was held in June 2004 with the participation of 500 attendees. The theme of the Symposium was Research and Prevention of Birth Defects. A group of experts in the area of Perinatology, Pediatrics, Folic Acid Promotion, Cardiology and CSHCN providers presented the latest information and the challenge for health professionals. (4) An article was published in a professional journal aimed at improving primary health care physician's skills for the promotion of the folic acid message. The journal was mailed to 9,980 physicians across the Island.

The staff of the Folic Acid Campaign did not miss any opportunity to participate in professional meetings with it exhibits on Folic Acid. These included OB/Gyn, Mental Health Conference, the Symposium on Sexual Health and the NBDPN Conference.

Another strategy for delivering the message is the participation in health fairs across the Island,

where FA information is offered to WRA and the general public.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyra	l of		
	DHC	ES	PBS	IB
1. Increase awareness among primary care providers of need to recommend daily folic acid consumption.				X
2. Use trained insurance company personnel to promote use of daily folic acid in medical offices.				X
3. Hold meetings with key stakeholders to develop strategies directed at increasing use of folic acid.				X
4. Promote the use of the Folic Acid Educational Module among students of the Department of Education.			X	
5. Coordinate activities to increase awareness among the public at large of birth defects and strategies to prevent them.			X	
6. Coordinate the observance of Folic Acid Awareness Day in local university campuses.			X	
7. Educate students in health related fields of their role in promoting the use of folic acid.			X	
8. Continue interagency collaborative efforts to promote use of folic acid in the media.				X
9. Promote the establishment of a State Coalition for birth Defect Prevention.				X
10. Evaluate level of folic acid awareness and consumption among women of reproductive age.				Х

### b. Current Activities

During FY 2004-2005, the Folic Acid Campaign continues its active participation in diverse activities, maintaining a continuous presence in conferences, short lectures, training for trainers activities, and providing individual orientations (face to face and by phone). During this fiscal year, we participated in a total of 33 health fairs some of them especially designed for health employees, reaching nearly 3,000 persons. On October 14, 2004 and with the collaboration of the MCH regional staff, the program coordinated the Third Folic Acid Awareness Day in eleven (11) campuses of the University of Puerto Rico, reaching approximately 1,600 college students. Promotional materials and information brochures were provided in each site.

In terms of educational activities for health professionals, during the current fiscal year the Folic Acid Campaign provided training on Birth Defects Surveillance and folic acid promotion to the staff of 22 hospitals (50% of the birthing hospitals in Puerto Rico). We also published an article in the School of Nursing Journal Impulso, which is distributed to every registered nurse in Puerto Rico.

Finally, the Folic Acid Campaign staff is working on the expansion of prevention messages for other birth defects and in the design of a media campaign that will begin at the end of this fiscal year. In order to be successful in this area, part of our staff received training on Health Communication, offered by the Johns Hopkins University and sponsored by the Secretariat for Health Promotion.

# c. Plan for the Coming Year

For the coming year, the Folic Acid Campaign needs to reinforce the strategies used with the insurance companies to increase the awareness among their primary care providers. To attain this, our staff will be providing training in folic acid consumption and NTD's prevention to the staff of the insurance companies in order to educate them to provide face to face information to physicians at least once a year.

The collaboration with the Department of Education and other state agencies will continue to maintain the folic acid messages up to date and to promote the behavioral changes needed to achieve the prevention of NTD's. During next fiscal year we will be encouraging the use and implementation of a folic acid peers curriculum to promote awareness of folic acid messages among students of health and education. We will continue with the participation in health fairs at the community level, in schools, universities and public and private agencies.

One important objective of the Folic Acid Campaign staff for the coming year is to develop the Birth Defects Prevention Council in Puerto Rico. During the next fiscal year our staff and collaborators will be defining and formalizing the roles of the diverse partners representing community, private and public agencies.

State Performance Measure 4: To increase the number of conditions tracked by the Birth Defect Surveillance System.

-							
Tracking Performa [Secs 485 (2)(2)(B)(iii	Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	100	26	26	52	57		
Annual Indicator	100.0	26.1	26.1	56.5	56.5		
Numerator	2	6	6	13	13		
Denominator	2	23	23	23	23		
Is the Data Provisional or Final?				Final			
	2005	2006	2007	2008	2009		
Annual Performance Objective	57	80	90	90	100		

#### Notes - 2002

The performance measure was met already. It will be replaced by next year.

## Notes - 2003

During year 2000 the performance measure was already met, therefore the performance measure was rephrased. Ten (10) additional conditions are at present under consideration by the Birth Defects Surveillance System Interagency Committee to account for a total of 23 conditions in the future.

Corrections were done to data reported for FY 2001, 2002 and 2003. The correct denominator for years 2001, 2002 and 2003 is twenty-three (23). The annual indicator for years 2001 and 2002 is twenty-six percent (26%); for year 2003 is fifty seven percent (57%).

#### Notes - 2004

In year 2000 the performance measure was already met, therefore this performance measure was modified in year 2001 to include at least 23 birth defects categories by year 2005. Corrections were done to data reported for FY 2001, 2002, and 2003. The correct denominator for years 2001, 2002, and 2003 is twenty-three (23). The correct annual indicator for years 2001 and 2002 is twenty-six percent (26%). The correct annual performance objectives for years 2001 and 2002 are twenty-six (26%). For year 2003, the correct annual indicator and annual performance objective is fifty-seven percent (57%). In year 2002, we planned the inclusion of seven (7) additional conditions and it was implemented in year 2003, changing the numerator to thirteen (13).

In year 2005, the Birth Defects Surveillance System personnel revised the categories of the birth defects based in the nature of the defect and the International Classifications of Disease (ICD-9 codes). As a result, this performance measure was modified to include at least 55 birth defects diagnoses by year 2010. After this revision the new classification is distributed as follows: a total of 38 birth defects diagnoses at present under surveillance distributed in 10 birth defects categories. The SPM#4 is phrased as follows: Develop and maintain an active surveillance system for at least 55 birth defects by the year 2010. We will continue to add more birth defects diagnoses.

## a. Last Year's Accomplishments

In January 2003 additional birth defects were added to the case definition: Omphalocele, Trisomy 18 and 13, albinism, ambiguous genitalia, congenital heart defects, and conjoined twins. Trainings on the additional birth defects where offered throughout the Island. Active surveillance continues, and the promotion of genetic counseling, counseling for prevention of NTD recurrence and the promotion of early access to health services. Results were shared with health professionals and decision makers at all levels. A draft for a mandate to regulate the birth defects surveillance in the Island was submitted to the Department of Health authorities.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Increase to 48 the birth defects included in the Surveillance System.			X		
2. Continue with current surveillance activities.			X		
3. Coordinate activities to celebrate the birth defects prevention month in Puerto Rico.			X		
4. Review and expand the current referral system for children with birth defects.		X			
5. Develop and implement the Maternal Risk Factor Surveillance Project.				X	
6. Develop educational material on the ten additional birth defects.			X		
7. Offer trainings on additional birth defects.				X	
8. Continue with training to hospitals' staff.				X	
9. Promote compliance with Law #351.				X	
10. Develop regulations for the implementation of Law #351.				X	

### b. Current Activities

We continue with the surveillance activities of the 13 categories or birth defects diagnoses included in the case definition. Short trainings were offered to health professionals in 50% of the birthing and pediatric hospitals throughout the Island. Continuous activities include: 1) dissemination of information related to the prevention of risk factors associated with the index cases in health fairs and talks, 2) collaborative activities between health agencies for the dissemination of prevention efforts and the early diagnosis and access to habilitation services, 3) dissemination of data related to birth defects prevalence by request of media, agencies and the general public, 4) sharing our results in health professionals' conferences at local and national levels, 5) conducting a cleft lip and palate case-control study with the assistance of the University of PR in Cayey, and other observational studies, 6) sharing surveillance data at the local and national levels (MCH, CSHCN, NBDPN and CDC) throughout the year, through reports, requests and presentations. On September 16, 2004, Law #351 was approved to regulate the birth defects surveillance in the Island and to establish a mandate for the report of every suspected or confirmed case of any birth defect. This law will promote the availability of standardized data, the proper documentation among data sources and the early referral for access to health and early intervention services. The Department of Health will be responsible for contacting affected families to offer genetic counseling and orientation. We started the development of a Birth Defect Prevention Coalition for Puerto Rico. The effort was an initiative of the Department of Health in collaboration with representatives from the public and private sector. Development of the protocol for the Maternal Risk Factors Surveillance Project started in November 2004.

On January 26, 2005, the Birth Defect Surveillance System of Puerto Rico received an award from the National Birth Defects Prevention Network (NBDPN) honoring the outstanding activities of our Program in the promotion of public awareness of birth defects through innovative and collaborative education and prevention efforts.

In 2005, the Birth Defects Surveillance System revised the categories of the birth defects based on the nature of the defect and the International Classifications of Disease (ICD-9 codes). After this revision the new classification is as follows: a total of 38 birth defects diagnoses under surveillance distributed in 10 birth defects categories. Therefore, we will revise the SPM #4, to change birth defects categories for birth defects diagnoses. We will continue to add more birth defects diagnoses.

# c. Plan for the Coming Year

We will continue the development of the Birth Defects Prevention Coalition. We are planning to maintain active surveillance and add more birth defects diagnoses for the next year for a total of at least 48 birth defects diagnoses. For 2010 we plan to have at least 55 birth defects diagnoses. The process will include training sessions to health professionals throughout the Island. We will continue the surveillance activities and the implementation of the Law #351 for Birth Defects Surveillance in the Island; the coordination of activities to celebrate the birth defect prevention month in Puerto Rico in January 2006; the development and implementation of the Maternal Risk Factor Surveillance Project related to birth defects; and developing educational material on the additional birth defects.

State Performance Measure 5: Prevalence of tobacco use among pregnant women

Tracking Performance Measures
[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	4.3	3.5	3.0	2.5	2.0
Annual Indicator	3.7		4.1	2.8	3.6
Numerator	82		94	18	36
Denominator	2223		2310	636	1004
Is the Data Provisional or Final?				Provisional	Final
	2005	2006	2007	2008	2009
Annual Performance Objective	1.5	1.5	1.5	1.5	1.5

#### Notes - 2002

Figure from ESMIPR 2002 (Puerto Rico PRAMS-like survey)

#### Notes - 2003

The data for this PM is obtained from a biennial customized PRAMS-like survey (ESMIPR). This survey is administered to recent mothers in postpartum wards. This year (2004) the questionnaire had to be submitted for review and approval to the IRB and HIPAA Committees of the School of Medicine. Unfortunately, it took four months to obtain the final authorization of both committees. Currently we are in the process of collecting the data from a representative sample of 1000 cases in 28 birthing hospitals. Provisional data is provided.

### Notes - 2004

Data collected through the PRAMS like survey conducted in 2004.

## a. Last Year's Accomplishments

The MCH Division of the PRDH conducts a PRAMS-like surveillance study, the "Estudio de Salud Materno Infantil de PR" (PR Maternal and Child Health Study) biennially. The latest survey was conducted in 2004. In that study, interviews with 1,004 women in the immediate post partum period were carried out. The prevalence of tobacco use among pregnant women was calculated in the 2004 survey at 3.6%, significantly higher than the 1.0% reported by vital statistics (2001). Low birth weight is the number one cause associated with IM in PR. It has been scientifically corroborated that women who smoke are at a higher risk of having a LBW infant.

The HVNs have continued implementing the smoking cessation program that was designed in 2001 under the auspices of AMCHP's Tobacco-Free Futures Mini-Grant. This project allowed us to convene a panel of experts in smoking cessation and education to design a comprehensive program for our pregnant smokers. The smoking cessation program is based on the USPHS Guidelines for Smoking Cessation and uses DiClemente and Prochaska's Transtheoretical Model as the basis for designing the most appropriate intervention. The HVN uses the "Perfil de la Participante," which is the instrument designed to collect information regarding smoking status, to determine addiction severity, susceptibility to change and level of motivation and support. The self-help diary "Mi Gran Decision" is used as a complement to the HVN's intervention and is meant to guide the participant through a seven-day quitting process. In addition to this program, HVNs stress the importance of avoiding environmental tobacco smoke (ETS) for those women who, although not smokers themselves, live or work in proximity

to smokers.

Educational materials regarding both smoking and exposure to ETS are distributed in health fairs and other community education activities. In 2004, 350 educational activities on this topic reached 2,185 persons in the community.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities			Pyramid Level Service			
	DHC	ES	PBS	IB		
1. Share information of the survey with concerned individuals (ESMIPR).				X		
2. Screen HS participants for tobacco use and provide management according to the level of risk.	X					
3. Update providers' knowledge regarding screening and management of tobacco use during pregnancy.				X		
4. Include the topics of alcohol, tobacco and illicit drug use in patient orientations.			X			
5. Disseminate educational materials on adverse effect of high risk behaviors during pregnancy.			X			
6. Increase public awareness of poor birth outcomes associated with risky behaviors.			X			
7.						
8.						
9.						
10.						

### b. Current Activities

Home Visiting Nurses continue reporting the smoking status of their HVP participants. In calendar year 2004, 8.9% of our pregnant HVP participants reported smoking during the current pregnancy. The HVNs provided smoking cessation interventions following the Smoking Cessation protocol. Of the women who were identified as smokers, 94.2% complied with the smoking cessation intervention and reduced or discontinued their smoking practices. Culturally appropriate material is distributed at the community level and among HVP participants. In addition, the effects of high risk behaviors, including smoking, on the fetus is the topic of one of the two-hour sessions included as part of the "Comenzando Bien" Prenatal Curriculum. In 2004, 44 courses were held, with a total attendance of 538 participants.

In December 2004, the Department of Health established an island-wide toll free smoking quitline. Between December 2004 and April 2005, the quitline has assisted 879 smokers, of whom 413 (46.9%) are women. Unfortunately, the quitline does not ask women for pregnancy status.

The biennial PRAMS-like MCH survey ("Estudio de Salud Materno Infantil de PR") was carried out in 2004. Among other topics, it has a section of questions used to determine the prevalence of behavioral risk factors during pregnancy, such as smoking, alcohol and drug use. Information gathered will be shared with all stakeholders so that intervention strategies can be modified to effectively decrease smoking among pregnant women.

The interagency Tobacco Coalition continues to be active and continues its dissemination

activities. It publishes an informational bulletin that goes out to providers and interested parties several times a year.

# c. Plan for the Coming Year

Training sessions on appropriate interventions to reduce high risk behaviors among pregnant women will be held again in the coming year. The goal of these continuing education activities will be to update provider's knowledge regarding importance of screening and providing their patients smoking cessation interventions directed at reducing the prevalence of smoking in general, but particularly during pregnancy and the postpartum period. HVNs and CHWs will continue to promote smoking cessation among all those they come in contact during their daily activities in the community. HVNs will continue to screen all Home Visiting Program participants for tobacco use and provide management according to the level of risk. CHWs will include the topics of alcohol, tobacco and drug use in educational activities and individual orientations during their interventions in the community. These topics will be covered in depth during the prenatal and parenting courses the MCH staff offer in their respective municipalities.

Based on the needs assessment for the next cycle we need to continue the tracking of this performance measure.

## State Performance Measure 6: The birth rate among girls 10-14 years of age

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004	
Annual Performance Objective	2.1	2	2	2	2	
Annual Indicator	1.8	1.7	1.7	1.2	1.5	
Numerator	272	255	257	182	216	
Denominator	149816	149536	149536	149078	148916	
Is the Data Provisional or Final?				Provisional		
	2005	2006	2007	2008	2009	
Annual Performance Objective	1.1	1	1	1	1	

#### Notes - 2002

Numerator is from birth file data provided by Office for System Development. Denominator is an estimate provided by the Puerto Rico Planning Board for 2001.

# a. Last Year's Accomplishments

The 10 to 14 years old birth rate (per 1,000) in Puerto Rico had a 54% decrease from 2.6 per 1,000 in 1996 (it's peak) to 1.2 per 1,000 in 2003.

The MCH Staff carried out 1,595 small group orientations reaching 30,130 participants across the Island. Topics included: sex education and teen pregnancy prevention. Abstinence topic was given to 717 people in 213 small groups.

The Abstinence Education Project (PRAEP) reached 31,966 public school students through the "Sex Can Wait Curriculum" and extracurricular and peer group activities in 299 public schools in 56 municipalities islandwide. Other activities performed reached 22,436 participants through parent workshops, summer camps, conferences and other educational activities.

The plan to reduce health disparities in prenatal care, to support continued studies and prevent repeated teen births of the "Healthy Beginnings" Project and PRAEP continued in ten municipalities. One regional activity and 27 local meetings gathered 428 professionals in 14 municipalities to raise awareness of teen pregnancy issues and to identify needs to be addressed by the Project.

The Comprehensive Adolescent Health Program (SISA Program) included positive youth development in teen pregnancy prevention efforts through the Peer Teen Health Promoters' Program. A total of 522 students of 32 middle public schools served as Teen Health Promoters around the island. They carried out 228 activities reaching about 12,745 students. The Secretary of Health issued the Proclamation of March: Teen Pregnancy Prevention Month in Puerto Rico. During that month the SISA Youth Health Promoters held twenty-eight (28) teen pregnancy prevention activities reaching 1,646 adolescents islandwide.

The SISA Program sponsored a Positive Youth Development Training on April 29-30, 2004 in collaboration with the Konopka Institute. Representatives (33 persons) from the public and private sector -- including youth- attended the training. On June 5, 2004, training participants met to organize a Steering Committee, an action oriented group that will collaborate with SISA in developing a culturally appropriated curriculum on Positive Youth Development and a train-the-trainer handbook to be disseminated islandwide.

The partnership with the community-based organization COPI in Pinones led to the creation of "Jovenes Creando Conciencia" a group of 15 youth health promoters. They developed a social theater play about teen pregnancy, drugs and alcohol use that was presented to the community. The anthropological research about teen pregnancy continued with a focus group interview and individual in-depth interviews.

SISA efforts continued to promote the establishment of the public policy to reduce teen pregnancies. Collaboration in the "Coalicion Pro Salud Sexual Reproductiva del Adolescente" continued.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Continue the Abstinence Only Education Program with the Education Department to provide the Sex Can Wait Curriculum to 50,000 students during FY 2005-2006.				х
2. Offer educational activities addressing teen pregnancy prevention in schools and communities.			X	
3. Continue the support to the work and peer activities of the SISA Program's Youth Health Promoters in public schools.				Х
4. Identify and train teachers to develop after school programs promoting				

sexual abstinence in the Department of Education.			X
5. Distribute educational materials on topics related to teen pregnancy, abstinence and self-esteem.		Х	
6. Provide sex education and effective communication workshops to parents of school age children.		Х	
7. Promote the adoption of a public policy directed at reducing the rate of teen pregnancies.			X
8. Continue the organization of the Positive Youth Development Initiative for Puerto Rico.			X
9. Increase awareness on issues related to teen pregnancies among the general public.		Х	
10.			

### b. Current Activities

The MCH Staff has continued its teen pregnancy prevention educational activities in schools and communities islandwide.

The Abstinence Education Program (PRAEP) offered the "Sex Can Wait Curriculum" and peer group activities in public schools. Extracurricular and educational activities were offered. The Middle School Curriculum' Spanish translation was finished. Four summer camps for 12-17 year old youths are in progress. A youth art contest was done for a school calendar and youths are participating in the production of videos on sexual abstinence. Parental workshops have continued.

The "Healthy Beginnings" project to reduce repeated teen births and school dropouts continued until December 2004. A total of 73 MCH facilitators received the "Comenzando Bien" training to offer teens islandwide. Meanwhile, the SISA Program is developing a special curriculum for pregnant teens "Crianza con Amor" that stresses on preventing repeated teen pregnancies and promoting healthy parenting.

The Comprehensive Adolescent Health SISA Program is developing a study on 10-14 age teen pregnancies in collaboration with the Healthy Start Program. It includes the participation of SISA anthropologist, visiting MCH nurses and teen Healthy Start participants. Currently, the SISA Middle School Program has 582 youth health promoters in 40 schools which offer information and teen pregnancy prevention activities to their peers. The SISA Program creates awareness of the risk factors for teen pregnancy among students, health professionals and the public at large. A Youth Health Promoter's pilot initiative is been developed in two juvenile justice institutions. The Secretary of Health stated March as Teen Pregnancy Prevention Month in PR. The new Governor will consider the submitted Public Policy to Decrease Teen Pregnancies and the Plan of Action developed for Puerto Rico. The collaboration with "Red Pro Salud Sexual del Adolescente", an interagency and community network for teen pregnancy issues in PR continued.

The partnership with the "Jovenes Creando Conciencia" Teen Health Promoters of the Pinones community continued as they: 1) developed and administered a questionnaire targeted at community youth issues affecting their community; 2) participated in a hygiene training sponsored by SISA; 3) offered workshops on teen pregnancy prevention to local 5th and 6th graders (57 students); 4) participated in a communities' youth leadership training and; 5) developed a youth dance troupe. They will offer the personal hygiene workshop to girls aged 10-14 on June.

"Reto y Esperanza": Healthy Puerto Rican Youth Development, an initiative in collaboration with Rochester University, NY ACT for Youth and the Konopka Institute was established and a Steering Committee is working to develop a positive youth development curriculum and train

the trainer manual for Puerto Rico.

# c. Plan for the Coming Year

The MCH Staff will continue to provide adolescent pregnancy prevention educational activities and materials in schools, community programs or other entities.

The Abstinence Only Education Program (PRAEP) in conjunction with the Department of Education will continue to provide the Sex Can Wait Curriculum in its Spanish translation. Training regular teachers will prepare them to offer the curriculum. Peer group (AMORES) meetings in public schools will continue. These initiatives will also be implemented in private schools and among special health care need teens. Workshops for parents of school-aged children on communication about sexuality issues with their children will continue. A social theater company will offer public school's personnel a play about teen pregnancy issues and their role in preventing pregnant teen school drop outs including secondary abstinence to reduce repeated teen pregnancies. A TV media campaign will be started to promote teen sexual abstinence.

The Comprehensive Adolescent Health (SISA) Program will continue the study on 10-14 age teen pregnancies in PR in collaboration with the Healthy Start Program. The SISA Program will continue training youth health promoters in middle and high schools to give the message of teen pregnancy prevention to their peers through a variety of school based activities. A questionnaire to gather data on socio-demographic characteristics, health, skills and interests will be administered to the Peer Teen Health Promoters. The SISA Program will continue to work in developing awareness of teen pregnancy prevention giving special attention to educate parents to connect to their sons and daughters as a protection for conducts of risk. The "Hablando Claro" pilot Project will start in Naranjito, PR. The work to develop "Crianza con Amor" Curriculum for pregnant teens will continue. Collaboration with the "Red Pro Salud Sexual Reproductiva del Adolescente" and the "Red AMAME" for pregnant teens will continue. The development of the Directory of Teen Health Services in PR will continue in collaboration with government agencies and community based organizations. The collaboration with the Juvenile Justice Agency in PR will continue to develop the Youth Health Promoters. A pilot group will start in the female youth institution in Ponce.

The assistance to "Jovenes Creando Conciencia" Teen Health Promoters in Pinones will continue. The ethnographic study on teen pregnancy will be completed and a report will be submitted. An MCH Community worker will be offering services to the Pinones community on maternal-child and adolescent health.

The work of the Steering Committee of "Reto y Esperanza" Project will develop a positive youth development curriculum that will be tested in several sites. The Committee will also produce the train the trainer handbook. An evaluation plan will be implemented.

Based on the needs assessment for the next cycle we need to continue the tracking of this performance measure.

State Performance Measure 7: The rate of deaths to children aged 1-14 caused by asthma

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2000	2001	2002	2003	2004
Annual Performance Objective	0.2	0.2	0.2	0.2	0.2
Annual Indicator	0.3	0.2	0.3	0.0	0.2
Numerator	3	2	3	0	2
Denominator	906368	834720	891042	828372	815120
Is the Data Provisional or Final?				Final	Provisional
	2005	2006	2007	2008	2009
Annual Performance Objective	0.2	0.2	0.1	0.1	0.1

#### Notes - 2002

Numerator is from death file data provided by Office for System Development. Denominator is an estimate provided by the Puerto Rico Planning Board for 2001.

There was an error in the reported number for the denominator for year 2002. The correct figure for the denominator is 891042. The annual performance objective were revised for years 2002 - 2007.

#### Notes - 2003

Numerator is from death file data provided by the Office for System Development (ODSI). Denominator is an estimate provided by the Puerto Rico Planning Board for 2003. The data for year 2003 is provisional; no deaths were reported during 2003. For this reason, the annual performance objectives for years 2004-2007 will remain the same.

### Notes - 2004

Numerator is from death file data provided by the Office for System Development (ODSI). Denominator is an estimate provided by the Puerto Rico Planning Board for 2004.

# a. Last Year's Accomplishments

As part of Healthy People 2010 (HP2010), the Puerto Rico Department of Health (PRDOH) selected the Respiratory Diseases focus area, which contains 5 main objectives, related to asthma. The CDC Grant "Addressing Asthma from a Public Health Perspective" was awarded to the Division of Habilitation Services (DHS) at PRDOH, in 08/05/03. The grant has two main purposes: develop an Asthma Plan and implement an Asthma Surveillance System. The Plan will assist the PRDOH in achieving HP 2010 objectives. The main strength of the Plan is that members of the PR Asthma Coalition (PRAC) are participating in planning and implementation of activities. This level of involvement shows their commitment toward reducing the morbidity and mortality associated to asthma.

The infrastructure and computer program for the Puerto Rico Asthma Surveillance System (PRASS) were created and strengthened. Meetings were held with major insurance companies, which signed Memorandums of Understandings to provide asthma utilization claims data to the PRASS. These include hospitalizations, ER visits, outpatient clinic visits and prescription medications filled. This will help to monitor trends in the burden of asthma, guide public health action, help in the establishment of the Asthma Plan and evaluate interventions.

The PRDOH participated in the coordination of World Asthma Day 2004. A media tour was developed and also an itinerary of activities including 3 symposiums for physicians regarding the controversies in asthma management, educational activities in pharmacies, shopping malls, HMO's and schools. Two brochures were developed, one describing the PRAC and the other containing information about asthma and the action plan for asthma management. A press conference was held in 05/03/04 with the Secretary of Health who provided updated data on asthma morbidity and mortality from the PRASS.

The Environmental Protection Agency (EPA) funded an asthma project called Proyecto Aire, a collaborative effort with the University of PR (UPR) and the PRDOH. UPR provides asthma education at community centers and schools to asthmatics and their families; PRDOH recruited UPR-trained outreach workers to conduct in-home site visits to 100 families. Orientation on environmental triggers was provided and a pre and post visit questionnaire was administered to assess knowledge.

The PRDOH raised awareness about asthma in PR and the Asthma Plan through the Chronic Diseases Conference held in 06/04 and the Public Health Conference held in 09/04.

PRDOH has been represented at the Board of Directors of the PRAC and the steering committee meetings of Allies Against Asthma of Puerto Rico.

The number of deaths due to asthma in children less than 14 years old (1999 to 2004) has been reported between 3 and 2 deaths each year. In 2003, there were no deaths registered but in 2004, two deaths were reported. The death rate for these years varied between 0.3 and 0.2 deaths per 100,000 population.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service				
	DHC	ES	PBS	IB	
1. Provide wrap-around services to low-income children with asthma.	X				
2. Promote policy changes for asthma care.				X	
3. Develop surveys to assess prevalence of asthma.				X	
4. Train health professionals in asthma management.				X	
5. Participate in other programs' committees.				X	
6. Collect asthma data, analyze, interpret and report findings and recommendations.				X	
7. Meet Healthy People 2010 objectives for respiratory diseases.				X	
8. Collaborate with other asthma educational programs.				X	
9. Develop a collaborative State Asthma Plan as part of the CDC Asthma Grant.				X	
10. Raise awareness and visibility about asthma in PR and the State Asthma Plan.			X		

### b. Current Activities

The PRDOH has an ongoing asthma surveillance system that measures morbidity, mortality, and work-related asthma. The surveillance system provides information helpful for the establishment of an island-wide comprehensive asthma plan and to evaluate asthma interventions. The first surveillance report was completed and includes mortality and prevalence data. This report is still under revision. The State Asthma Plan will be completed

with the collaboration of the PRAC by August 2005.

As part of the Asthma Awareness Month, the PRDOH together with the PRAC participated in an interactive asthma education activity entitled " Addressing Asthma From a Public Health Perspective". Fifty health professionals from the health regions participated and were offered continuing medical education credits.

The DHS and the PRAC will implement a small-scale educational intervention for physicians by August 2005. Primary care physicians in a selected geographic area with high rates of asthma morbidity and mortality will be trained on the NAEPP (National Asthma Education and Prevention Program) asthma treatment guidelines. The major health insurance companies will help to identify primary care physicians. Training needs will be assessed and an expert pulmonologist will develop a tailored curriculum. This will be the beginning of future interventions island wide with physicians once the State Asthma Plan is completed.

The DHS continues funding the Pediatric Pulmonary Program of the Cardiovascular Center of PR with Title V funds in order to provide wrap-around services to asthmatic children from low-income families. Activities held during this fiscal year include:

- \* Monthly training sessions for children over 7 years of age and families on the identification of triggers, use of the peak-flow meter and management according to an Asthma Action Plan elaborated by the neurologist with follow up in coordination with the primary physician. A total of 115 participants, including 52 adults and 63 children were benefited.
- \* Administration of Palizumab for the prevention of Respiratory Syncitial Virus to premature infants
- \* Pulmonary function tests administered to asthmatic children during activities in the communities.
- \* Participation of a multidisciplinary team in TV and radio to discuss current asthma isssues (fairs, schools, etc).
- \* Partnered family advocacy effort for the implementation of Law #482 (Sept 7, 2004) to include coverage of mechanical ventilators under the Government Insurance Card required for life preservation.

DHS continues its involvement with the development and implementation of the State Asthma Plan This will also enable PRDOH to meet the HP2010 objectives for Respiratory Diseases.

The PRDOH is offering support in analyzing data collected by the UPR-trained asthma outreach workers who conduct in-home educational site visits. This is part of an ongoing collaborative effort with the EPA funded asthma educational project ("Proyecto Aire") of the UPR.

# c. Plan for the Coming Year

The Surveillance System will submit the second surveillance report based on utilization claims, mortality, prevalence and work-related asthma data. The State Asthma Plan will be implemented with the collaboration of the PRAC based on Surveillance System findings and priority areas.

The PRAC in collaboration with the PRDOH and other entities will celebrate the 1st Asthma Congress in May 2006 focused on asthma health disparities. This will be an international forum to raise awareness about asthma health disparities and to present the State Asthma Plan and summary recommendations to key stakeholders, the general public, providers, practitioners, patients, and others. The impact of this Conference will be the sharing of collected asthma data on Puerto Ricans and analyses by attending experts. Workshops are being planned to elicit discussions, which may provide answers to the elevated prevalence and mortality in our

population.

An evaluation plan that measures the effectiveness of the asthma program and each intervention will be implemented. Information on each of the implementation phases will be collected and analyzed. Data-driven activities and interventions will be developed and effectiveness of the asthma program will be determined and evidenced through data collection and analysis.

The PRDOH Division of Habilitation Services will continue funding the Pediatric Pulmonary Program at the Cardiovascular Center of PR with Title V monies in order to provide wraparound services to asthmatic children from low-income families in need of specialized multidisciplinary services.

DHS will implement a strategic plan to meet the Healthy People 2010 objectives for Focus Area #24 Respiratory Diseases.

The PRDOH will support the PRAC in the coordination of the 2006 World Asthma Day activities.

State Performance Measure 8: To develop standards of care for at least two (2) conditions tracked by the Birth Defects Surveillance System per year.

Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]							
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	100	60	80	31	15		
Annual Indicator	40.0	40.0	40.0	15.4	15.4		
Numerator	2	2	2	2	2		
Denominator	5	5	5	13	13		
Is the Data Provisional or Final?				Final	Provisional		
	2005	2006	2007	2008	2009		
Annual Performance Objective	31	46	62	77			

#### Notes - 2002

During fiscal year 2003-2004 the existing standards of care for CSHCN will be revised and updated. For the next reporting year we plan to change this performance measure.

### Notes - 2003

Corrections were done to data reported for FY 2001 and 2002. The correct numerator for year 2001 is two (2). The correct numerator for year 2002 is two (2) and the denominator is five (5). During fiscal year 2004-2005, the Division decided to develop the standards of care for those conditions (13) included in the Birth Defects Surveillance System. This task will be

accomplished in collaboration with the expert group of the Birth Defects Surveillance System. The performance measure was rephrased to specify that the standards for at least two (2) conditions will be completed each year. The Annual Performance Objectives for years 2004-2007 were changed according to the number of conditions under the Birth Defects Surveillance System for reporting year 2003.

#### Notes - 2004

Corrections were done to data reported for 2001 and 2002. The correct numerator for 2001 and 2002 is two (2). Denominators for both years remain the same (5). For 2003, the Division of Habilitation Services decided to develop standards for the 13 conditions tracked by the Birth Defects Surveillance System.

During Fiscal Year 2004-2005, the Division of Habilitation Services decided to discontinue this performance measure (SPM 8). It was very difficult to involve experts to work on the standards of care. Our efforts will be geared to include primary physicians among the participants to the ongoing training on Birth Defects Surveillance System and on the procedures to refer these children to the Pediatric Centers upon identification, for follow up and management.

## a. Last Year's Accomplishments

The standards of care for Cleft Lip and Palate were completed. For the past three years the Division of Habilitation Services has been working with the implementation and maintenance of the Birth Defects Surveillance System (BDSS). The Division along with the Coordinator of the Folic Acid Campaign, the Legal Office of the Puerto Rico Department of Health and the Legislature, collaborated in the elaboration of a project, which became law in September 16, 2004 (Law #351) for the mandatory report of birth defects in Puerto Rico. This initiative will facilitate the early identification, referral and appropriate management of affected babies.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

, ·		,			
Activities		Pyramid Level of Service			
	DHC	ES	PBS	IB	
<ol> <li>Share developed guidelines for the surveillance of birth defects with the health insurance agencies.</li> </ol>				X	
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

### b. Current Activities

The Division of Habilitation Services will continue participating in the education of physicians and health related personnel, including Pediatric Centers' staff, through training sessions for each of the conditions included in the Birth Defects Surveillance System. Experts on the field will be invited as speakers; educational materials as well as continuous education credits will be available.

# c. Plan for the Coming Year

The Division of Habilitation Services decided to discontinue this performance measure. For future years, this Division will continue collaborating with the BDSS in their plans to complete the inclusion of up to 48 birth defects diagnoses and the trainings. Procedures will be established for the referral of identified babies and families to the closest Pediatric Center for further orientation regarding our specialized services in coordination with the primary physician.

### State Performance Measure 9: The rate of cesarean section in Puerto Rico

	Tracking Performance Measures [Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]						
Annual Objective and Performance Data	2000	2001	2002	2003	2004		
Annual Performance Objective	39.1	37	35	42.6	40.4		
Annual Indicator	39.1	42.0	44.8	46.1	47.7		
Numerator	23262	23536	23707	23443	24458		
Denominator	59460	55983	52871	50803	51223		
Is the Data Provisional or Final?				Final	Provisional		
	2005	2006	2007	2008	2009		
Annual Performance Objective	38.2	36	34.8	32.6	30.4		

### Notes - 2002

Numerator and denominator are from birth data file provided by Office for System Development.

# a. Last Year's Accomplishments

A key health issue and one the target of our investigations has been the increasing C/S rates in PR. Our rate has been increasing steadily. The upward trend began in 1995 and continues. In 1995, the C/S rate was 29.7%. By 2003 it was 46.1%. This represents a 55% increase. This rapid upturn coincides with the time HCR began in PR.

Three major studies have been conducted in order to identify factors that contribute to the increase. The initial study consisted of reviewing vital records of 183,400 C/S deliveries that took place from 1990 to 1999. This descriptive study revealed both primary and repeat c/s were increasing, were being performed mostly on workdays and during regular working hours, VBAC rates were extremely low (less than 8%) and that they were occurring mainly among the medically indigent. The highest rates were experienced by women between ages of 20-29, married and with more than 12 years of education. Based on this findings two additional studies have been conducted. One of them consisted of reviewing the medical records of women that had a C/S resulting in a live birth in 1999. A total of 560 records were included in the sample. For this purpose we translated and used an instrument developed by ACOG after receiving their authorization. The results of this study showed that there was no documented clinical risk factor in 77% of the reviewed records. In those cases where they were documented they were:

pregnancy associated hypertension 5%, diabetes 3% and others 15% (included anemia, hydramnios, chronic hypertension, others).

Most recently a self-administered survey was distributed to a representative sample of postpartum women who had a C/S delivery in 2004. The goal was to obtain information regarding their attitudes and beliefs, family influence characteristics of their medical care provider as well as demographic data and information related to their prenatal care and delivery.

In addition to conducting these investigations we have been actively involved in raising awareness of this issue. In February 2004, the MCH Division Director was a keynote speaker at the Annual ACOG Conference. In March 2004, the Secretary of Health, the Title V Director and Ob Consultant were interviewed for magazine article highlighting the high C/S rate in PR. We supported a legislative initiative to study the increasing rates of C/S. During our presentation we shared our results to date and offered recommendations for action based on them.

Our staff continue to educate the community on the risks associated with a C/S. During FY 2003-2004 (3,163) HVP participants and 563 community members participating in 41 CHW coordinated activities received this information.

Currently we are concluding our participation in an on line analytic training program, offered by the University of Rochester. The motive for participating has been to improve our ability to analyze the factors leading to the high C/S rate.

Figure 4b, State Performance Measures from the Annual Report Year Summary Sheet

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Monitor the tendency of cesarean section deliveries by institution for 2004 and provide feedback to the directors.				X
2. Continue analyzing the increasing C/S trend using vital records information.				X
3. Further enhance the skills and the analytical knowledge of key MCH staff members that will allow them to develop the expertise to analyze the underlying causes of the elevated C/S rates.				X
4. Share the results of all our investigations with the C/S Evaluation Committee, obtain their input and submit their conclusions and recommendations to the Secretary of Health.				x
5. Share the findings of the studies with the presidents of the local OB/GYN and ACOG chapters and other key health providers.				X
6. Educate and empower pregnant women with information on the indications for and risks associated with a C/S.			X	
7. Support public policies directed at reducing the increase in C/S rate.				X
8. Promote CME activities for perinatal health providers that include the topic of C/S.				X
9. Convene the C/S Committee at least 2 times during the year.				X
10.				

b. Current Activities

Our efforts to continue with a series of investigations that could shed light on the contributing factors for the elevated C/S rate in the Island are on going. We are currently concluding our analysis of the information collected from the self administered questionnaire administered to a representative sample of post partum women in 2004. To assist us in the analysis we have received technical assistance from the University of Rochester faculty that is providing us the on-line analytic training program (MATRICHS). Part of this TA included two day training during which topics such as Risk Statistics in MCH and using focus groups as an analytic tool were covered. During this TA we also had the opportunity to present them with the investigation protocol and questionnaire developed for the study. At the end of the TA we received valuable recommendations from them on how to proceed with data analysis.

In May 2005, the CDC sponsored a three-day technical assistance provided by an MCH epidemiologist, a CDC assignee to the Office of Public Health of Louisiana. The purpose of the TA was to review and make recommendations on current investigations being conducted by the MCH staff. During this time we had the opportunity to discuss with the expert the investigative process and analytic design associated with the post partum self administered questionnaire. He was able to submit recommendations to improve the analysis.

The information gathered in the study has been analyzed. The results suggest that the attitudes and beliefs of the medical provider influence the method of delivery. An abstract has been submitted and is pending approval to be presented at the Annual MCH Epidemiology Conference scheduled for December 2005.

During calendar year 2004, 5,162 participants of the Home Visiting Program received prenatal orientation concerning C/S. MCH Program CHW's have continued offering group orientations at the community level across the Island on risk associated with a C/S and empowering women to resist electively scheduled C/S.

The PR Birth Certificate was revised in 2004. Our MCH staff actively participated in the revision process. They made sure crucial information needed to analyze data related to C/S was retained in the new document. They also assisted the PR Department of Health Demographics Registry Office in training their personnel and hospital staff in their use. Six trainings were held for this purpose throughout the Island. Participants included perinatal health providers, including OB/GYN and Pediatrics specialists, nurses and demographic registry staff. We expect information gathered with its use, which began in January 1, 2005, we will gather better quality data. Having it will help us analyze factors contributing to pregnancy complications associated with C/S delivery and allow us to better understand the reasons for the rising C/S trend in PR.

# c. Plan for the Coming Year

The MCH Program will continue its efforts directed at reducing the rate of cesarean deliveries in Puerto Rico. Once all the studies are completed the information will be shared with all our partners such as health care providers the PR Chapters of ACOG and AAP, the OB/GYN and Pediatrics Chapters of the Puerto Rico Medical Association, the Association of Family Medicine Physicians, the PR College of Physicians, hospital administrators and health care insurance companies.

For this purpose the C-Section Evaluation Committee of Puerto Rico should be reactivated. Members should include Department of Health, PR Chapter ACOG, AAP, Puerto Rico Chapter Hospitals Assurance Committee Representative Center for Excellence in Women's Health Puerto Rico Health Insurance Administration Health Insurance Companies and Representatives from local Schools of Medicine. The Committee should be able to hold regular meetings to review all the collected information. Once the Committee has been able to analyze all the data we expect they are able to develop a strategic plan directed at reducing the C/S

rate in PR to levels established in the 2010 goal (26.5%). This plan will be formally presented to the Secretary of Health. If required we will promote public policy intended to reduce the trend of cesarean section rates in Puerto Rico.

Our MCH Section for Monitoring and Evaluation of the Health Status will continue to monitor the C/S rate in each of the birthing institutions and will be able to provide feedback on their performance to their directors.

Key findings and recommendations will be disseminated to the public and to professionals in the perinatal health care field.

All of our staff will continue to promote information regarding the risks of unnecessary C/S and will try to empower women to request a vaginal delivery and not an elective C/S.

Based on the needs assessment for the next cycle we need to continue the tracking of this performance measure.

### **E. OTHER PROGRAM ACTIVITIES**

#### **ENABLING SERVICES**

As required by law, the PR DoH has a Toll-Free Line (1-800-981-5721) to provide information about availability of health care and other services to the population. This service is contracted to Via Voice Solutions. As a result of the Health Care Reform, the Health Insurance Administration (ASES) as well as every contracted health insurance company are required to operate a toll-free line (TFL) for beneficiaries. Currently, there are several Toll-Free lines that may be used by clients and service providers:

ASES: 1-800-981-2737

Triple C: 1-800-981-1352 and 1-800-255-4375

MCS: 1-800-981-2554 Humana: 1-800-790-7305

Patients' Ombudsman Office: 1-800-981-0031

A total of 4628 calls requesting information were received at the state TFL and the central and regional offices of the MCH Division. In addition, APNI, a CBO that provides services to CSHCN families, received 600 calls.

#### POPULATION BASED

\*Regional MCH staff developed 14952 educational activities on MCH topics reaching 187,532 persons.

\*For FY 2003-2004, 73 participations in radio and TV programs addressing a variety of topics related to the MCH population were documented. Staff published over 20 short articles in regional newspapers, without cost to our program. Regional staff documented 648 participations in health fairs and multiphase clinics reaching over 51,500 people.

\*APNI carried out a series of activities for families of CSHCN. These included 18 workshops for parents reaching 155 persons and conferences all over the Island with the participation of more than 200 persons. An educational video, "The arrival of a Special Child", was shown in 19 locations in four regions.

\*The Naranjito Adolescent Program (NAP) held educational activities reaching 5,286 persons, and the

EMSC Program participated in 9 radio and TV programs and 3 awareness activities.

\*The Rape Victim Center performed 334 educational activities reaching 7820 persons. Program staff participated in 37 radio and TV programs and published 6 newspaper articles.

#### INFRASTRUCTURE BUILDING

- 1. Ongoing needs assessment, data analysis and other related activities.
- \*Development and dissemination of the Integrated Index of MCH by municipality for 2003.
- \*Analysis of deaths due to unintentional injuries in children and adolescents (0-24 years) in 2003.
- \*Comprehensive needs assessment of the youth population in PR.
- 2. The MCH Director carried out 5 presentations entitled "Signs and Symptoms of the PR MCH Status" reaching 532 Health Professionals, including OB/GYNs at the Sunshine Seminar, Pediatric Residents, and others. He also participated in the Healthy Start Regional Meeting in NJ, where he made the presentation "Title V and the Healthy Start Project in PR: A Model of Service Integration for WCBA, Children and Families."
- 3. The article "Analysis of Infant Mortality in Puerto Rico" was published in the MMWR. Another article about C/S in Puerto Rico was published in "Nueva Vida" magazine.
- 4. About 45 legislative bills dealing with health policies benefiting the MCH/CSHCN population were presented at the legislature. Several of these bills were enacted into laws. Examples of these are: \*Law 79 March 2004 to prohibit the administration of any breast milk substitute to newborns without the written consent of the mother. Any institution that violates this law will be fined.
- \*Law 95 April 2004 prohibits discrimination against women who breastfeed in any public setting.
- \*Law 220 August 2004 to establish the Bill of Rights for pregnant teens enrolled in public schools.
- \*Law 318 December 2003-to designate the PR DoH as responsible for developing and implementing public policy for evaluation, management and registry of children and adults with autism.
- \*Law No. 351 September 2004: To establish a Birth Defect Registry at the PRDoH. This law requires that all providers and agencies which come in contact with cases of birth defects must report them to the DoH regardless of gestational age.

These public policies will help us toward the achievement of NPM 11, SPM 3, and others.

- 4. Standard development and guidances.
- \*New data collection records for Home Visiting Program participants.
- \*New Norms and Procedures Manual for Community Health Workers.
- \*Rape Victim Center developed a Protocol for intervention with rape victims in hospitals and distributed 525 copies of it in hospitals Islandwide.
- 5.Data sharing: The 4th Annual SSDI Conference was celebrated with the participation of 320 health professionals.
- 6. Professional Development: During the past FY we provided 6 CME activities aimed at prenatal care providers in different parts of the Island. The topics covered were: Overview of the MCH health status, perinatal depression, and the importance of oral health services in pregnant women. A total of 386 dentists, MDs, RN and Dental Assistants were registered.
- 7. The MCH staff at the state, regional and local levels participated in over 1500 meetings with different public and private partners.
- 8. The Healthy Start Consortium held 5 meetings during the past fiscal year. The RWGs of the SSDI Project met regularly during the reporting period.
- 9. Technical Assistance (TA)

- \*The Adolescent Program (SISA) sponsored a TA on Positive Youth Development in collaboration with the Konopka Institute.
- \*MCH staff also provided TA to four students of the Evaluation Program of the PR School of Public Health in MCH related topics.
- 10. The staff of the Monitoring and Evaluation Section participated in several training activities, such as:
- \*MCH Epi Training sponsored by AMCHP/CDC.
- \*Lineal Model Analysis supported by the UPR School of Public Health.
- \*Evidence Based Evaluation--supported by MCHB/CDC.
- \*Planning, Implementation and Evaluation of MCH Programs--supported by MCHB/CDC
- \*Use of Geographic Information Systems (GIS, Arc View) in Public Health.
- 11. MCH Program granted support to the NAP, and also provided 9 letters of support to other community based programs and initiatives.

#### F. TECHNICAL ASSISTANCE

The new Guidance set for the Title V Application and Annual Report requires that States report progress in achieving the established annual performance indicator for each of the 18 National Performance Measures, all the State Negotiated PMs (9 in PR), 11 HSCIs and other health status and sociodemographic indicators and 6 outcome measures. This is great challenge for those jurisdictions with limited resources and which at the same time are left out of national surveys that provide the data for some of the PMs. The latest example of a survey which did not consider the needs of the jurisdictions is the SLAITS. This survey will help the States by providing the data to monitor some of the PMs concerning the CSHCN population. However, the jurisdictions must report progress on performance measures #02, #03, #04, #05 and #6 even though they were not included in the SLAITS.

Currently, the PR CSHCN program does not have the needed data to monitor the progress of the five national performance measures mentioned earlier. There are no data for either the denominator nor the numerator of these performance measures.

Since in 2005-2006 states and jurisdictions will have to perform the comprehensive and mandated 5 year needs assessment, a TA concerning the needs assessment of the population of CSHCN is desperately needed. Some of the questions that need to be answered for the CSHCN include:

- 1. How many children with special health care needs are there in the Island?
- 2. What is the distribution by age group?
- 3. What are the most prevalent conditions?
- 4. In which geographical areas do these children live?
- 5. What services are available for them and where?
- 6. How many providers are there according to identified prevalent conditions, and where do they practice across the Island?
- 7. Others.

Initial conversations with Dr. Michael Kogan have already taken place on Puerto Rico's need to collect pertinent data for CSHCN. The Division of Habilitative Services firmly believes it is necessary to request TA for this endeavor in order to be successful.

The TA should be geared to assist us in designing the most appropriate process to gather the needed information to answer the aforementioned questions, what are the minimal resources needed to carry out the task and to obtain reliable and useful data.

Therefore we request that our MCHB Project Officer come to PR, gain knowledge of our service delivery system and recommend the appropriate MCH staff person to assist us in the process of developing, adapting, testing and administering the Spanish SLAITS CSHCN survey to the general

population.

Technical assistance also is being requested to assist the Title V CSHCN Program in the planning and development phases of a comprehensive strategic transition plan partnering with all stakeholders to comply with the NPM#6.

### **V. BUDGET NARRATIVE**

#### A. EXPENDITURES

Completion of Budget Forms

Please refer to budget columns of Form 2, Form 3, Form 4 and Form 5 for FY 2003-2004. Estimates had to be used in providing budget and expenditure details. Breakdown of expenditures by type of services is a very difficult task when we try to assess the performance of a public health professional. This task is quite easy at the first level of the pyramid related to direct services. At this level, we know who serves the different groups of the MCH population and the amount of time dedicated to each of the subgroups, allowing us to determine the expenditures by type of individuals served. But trying to estimate the amount of time dedicated to each of the subgroups comprising the MCH population, as well as the time dedicated to perform enabling, population-based or infrastructure building services, is not an easy task. For this reason, estimates had to be made and this may lead to discrepancies between the budgeted and the expended figures by levels of the pyramid.

### **B. BUDGET**

Program allocations have taken into account the 30-30-30-10 requirements established by Title V. Efforts are made to match funds according to the identified needs through the four levels of the MCH pyramid, as well as the three groups of individuals that comprise the target population.

Puerto Rico assures that the MCH funds are used for the purposes outlined in Title V, Section 505 of the Social Security Act. Traditionally, a fair method has been used to allocate Title V funds among individuals and geographic areas having unmet needs. As the implementation phase of the HCR reached its final phase, the fair allocation of funds is guided by an Integrated Index of Maternal and Infant Health Status (IIMIHS) developed by the MCH Division to assess the health needs of the target population by municipality. One of the benefits of using this Index is that the information necessary to evaluate each of its variables is available on an ongoing basis through analysis of birth and death files. Definitely, the IIMIHS is a useful tool guiding the allocation of resources for Components A & B across geographical areas (Table II-1). The Division of CSHCN allocates Title V funds guided by the needs assessment's findings and the national and state performance measures.

Allocations by Levels of the Pyramid:

Direct Services: Funds will be used to purchase contraceptive methods to support the family planning services rendered through the health care reform for women holding the GIP. Even though the family planning services, including sterilization of males and females, are included in the GIP, the contraceptive methods are not included in the benefit package. Also, salaries of the 7 Pediatric Centers providers are included in this item.

Enabling Services: A significant amount of Title V funds is needed to support salaries of Home Visiting Nurses, perinatal nurses, community health workers, health educators, payment of local travel expenses of HVNs, community health workers and other MCH personnel and for the Toll Free Information line. Funds are alloted to cover expenses for an information line on services available at the Pediatric Centers. As of March 2005, we account for 109 Home Visiting Nurses, 85 community health workers, 9 perinatal nurses and 5 health educators across the Island. At regional levels we account with 8 teams comprised of the regional MCH director, coordinator of reproductive health, coordinator of preventive services for children, coordinator of adolescent health, and support administrative staff. At central level we account 19 regular positions and 9 contracts. Contracts positions include a biostatistician, 1 epidemiologist, 2 evaluators and programmer and to support a community based organization that promote adolescent health (The Naranjito Adolescent Program).

Population-Based Services: Title V monies are used to sustain the NTD prevention campaign, injury prevention, public education, purchase of educational materials according to the performance measures, incentives that promote the toll-free line and convey health promotion messages, the staff of the Comprehensive Adolescent Health Program (SISA) and a wide array of health promotion

messages.

Infrastructure Building: To sustain the infrastructure of MCH/CSHCN programs, funds are used for the salaries of central and regional staff, for needs assessment and other core functions, equipment, professional development, the interactive education program, the purchase of computers, e-mail, support of applied investigations, surveillance, travel to required meetings, conferences and training in the mainland, and other related activities.

A total of 35% of Title V Block Grant Funds are allocated for the CSHCN program. Thirty percent (30%) is used to provide for services at the Pediatric Centers islandwide. This includes salaries and benefits of the staff, professional service contracts, medications not covered by GIP, nutritional supplements and assistive technology devices considering the established procedures. The other five percent (5%) is used to cover the administrative costs for central level and the seven (7) Pediatric Centers.

The needs of CSHCN identified through the needs assessment support our efforts to make specialized services available through the Pediatric Centers. The Metropolitan Area Pediatric Center, administratively under the Pediatric University Hospital for the past ten years, remains a supra tertiary referral center and provides services not available at the regions for children and families referred by the other six Pediatric Centers. The Metropolitan Area Center offers a great variety of subspecialized services to our population.

At Central Level, the Division of Habilitation Services accounts for a total of 26 positions: 17 regular positions, 8 contracts and 1 CDC Fellow. Contract positions include: 1 Evaluator, 1 Folic Acid Campaign and Birth Defects Surveillance System Coordinator, 1 genetic counselor, 1 Information System Administrator, 2 Epidemiologists, one for the CSHCN Title V Program and one for the Asthma Surveillance System, 1 Universal Newborn Hearing Screening Coordinator and 1 Asthma Project Coordinator. The CDC Fellow is assigned for the planning, development and implementation of an Autism Surveillance System. Positions paid by Title V funds include 14 at Central Level and 139 at the regional levels for a total of 153 positions. For more detail of the positions, please see Table V-3.

The Pediatric Centers bill the insurance companies for the services provided to the CSHCN under the GIP. As the reimbursement process is becoming more efficient, an improvement in the amount of money collected is observed. We account for \$523,331.00 available at the DoH, income generated during 2004-2005. These funds will be used to support the billing unit and provide for their priority needs, to cover some of the non-recurrent expenses at the Centers, to continue supporting the information system and to pay for additional subspecialty services at the pediatric centers.

State dollars used to provide services to the MCH population surpass by many times the requirements for the match. State funds appropriations are used for the GIP and the implementation of a broad array of programs and services that contribute to improve the health and well being of the MCH populations. Table V-1 presents a list of several programs supported by State dollars.

In addition to MCH dollars and the State funds listed in Table V-1, there are other federal sources of funds that contribute to the achievement of the MCH outcomes. These are included in Form #2.

Budget documentation: The Fiscal Affairs Office of the Department of Health and the Office of Federal Affairs maintain budget documentation for Title V funding and expenditures consistent with section 505(a)(1).

Allocations for FY 2005-2006: The estimated amount of money to run the MCH/CSHCN programs during FY 2005-2006 is as follows:

Federal: \$16,981,400.00 Unobligated: \$6,169,916.00

(FY 2004-2005)

State Matching: \$17,363,487.00 Program Income: \$523,331.00

Total: \$41,038,134.00

The unobligated balance allows us to continue running both MCH/CSHCN programs during the first trimester of FY 2005-2006. As everybody knows, the funds herein requested are not available until late November or early December of the fiscal year.

## Allocation by MCH Population Groups:

- A) \$5,094,420 (30%): for the provision of services to pregnant women, mothers & infants.
- B) \$5,094,420 (30%): for the provision of preventive services for children.
- C) \$5,094,420 (30%): for the provision of services to CSHCN.
- D) \$1,698,140 (10%): From this amount, 5% is for program administration of Components A & B; and 5% for administration of the CSHCN program.

Administration: Up to 10 percent of the federal allocation is used to support salaries of administrative staff, utilities, internal audit, newspaper announcements, office supplies, duplication of documents, mailing, AMCHP annual membership and others. The CSHCN Program covers part of its administrative costs from the 35% allocated from the MCH Block Grant.

### Other Requirements

Maintenance of Efforts: Puerto Rico is in compliance with maintenance of effort requirements as described in Section 505(a)(4). In fact, PR exceeded efforts of the 1989 program year. As of December 2004, there were 1,521,981 individuals with the GIP in Puerto Rico. Among these, 383,941 were women (14-49 years of age) and 24,374 were infants <1 years of age. Close to 431,123 were children (>1-19 years) including CSHCN.

During the FY 2004-2005, of all individuals holding the GIP, the MCH population represented 55.2%. The annual cost per person was \$861.96 (\$71.83 per month). The Table V-2 summarizes the sources of the budget used to pay for the health services of the population holding the GIP.

Considering that 55.2% (838,935) of the beneficiaries of the GIP represent the MCH population, it is estimated that PR invested over \$723,595,556.80 million in state and local funds to pay for the MCH services. We assume that 33% or \$238,786,533.00 million were invested in preventive and primary services for the MCH population. In addition, about \$159.3 million of Medicaid and \$42.3 millions of CHIP were also used for this segment of the population.

Several earmarked state funds allocated for special services and programs were also identified. These include \$1,031,038.00 for the Pediatric AIDS program, \$200,000 for the Newborn Screening for Hereditary Diseases Program, \$100,000 for the EMSC program, \$7,469,430 to support 132 children and adolescents with Catastrophic Illnesses and others totaling \$8,800,468.00. Definitely, the Commonwealth of Puerto Rico surpasses the matching requirements of Title V. (Table V-1)

### VI. REPORTING FORMS-GENERAL INFORMATION

Please refer to Forms 2-21, completed by the state as part of its online application.

### VII. PERFORMANCE AND OUTCOME MEASURE DETAIL SHEETS

For the National Performance Measures, detail sheets are provided as a part of the Guidance. States create one detail sheet for each state performance measure; to view these detail sheets please refer to Form 16 in the Forms section of the online application.

## VIII. GLOSSARY

A standard glossary is provided as a part of the Guidance; if the state has also provided a state-specific glossary, it will appear as an attachment to this section.

### IX. TECHNICAL NOTE

Please refer to Section IX of the Guidance.

### X. APPENDICES AND STATE SUPPORTING DOCUMENTS

## A. NEEDS ASSESSMENT

Please refer to Section II attachments, if provided.

#### B. ALL REPORTING FORMS

Please refer to Forms 2-21 completed as part of the online application.

## C. ORGANIZATIONAL CHARTS AND ALL OTHER STATE SUPPORTING DOCUMENTS

Please refer to Section III, C "Organizational Structure".

### D. ANNUAL REPORT DATA

This requirement is fulfilled by the completion of the online narrative and forms; please refer to those sections.